

**STAFF PERSPECTIVES ON GETTING TO KNOW  
AN INDIVIDUAL WITH DEMENTIA**

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## **ABSTRACT**

**Background:** Previously, a diagnosis of dementia was associated with decline, with little hope for positive intervention, having implications on care practice. This has meant little focus on individuals' needs in care homes. Over the past 20 years there has been a gradual shift towards emphasising the importance of the environment on individuals' psychological wellbeing, with relationships being central to this.

**Objectives:** This study aimed to explore staff's perspectives on getting to know a person with dementia in a care home environment, bearing in mind the recent literature on the positive benefits of knowing a person's life history, and what helps or gets in the way of getting to know a person in a care home setting.

**Design:** This was an exploratory study using thematic analysis, taking an inductive approach. A critical realist position was taken which allowed both the content and the context of staff's experiences to be considered.

**Method:** Semi-structured interviews were used with nine members of staff across three care home settings. Data was analysed using thematic analysis, based on Braun and Clarke (2006).

**Results:** Three themes conceptualising staff's experiences of getting to know a person with dementia are proposed: i) The development of a 'risk' lens? ii) challenges in what is valued by staff and organisations: a need for congruency? and iii) creating fertile ground for building trusting relationships.

**Conclusions:** This study suggests that psychological safety for everyone in the system is paramount to enable trusting relationships to be built. Knowing a person with dementia's life history and spending time '*being with*' them creates opportunities to enhance identity and increase wellbeing for clients and staff. The importance of the impact of historical and current social and political influences is highlighted and recommendations made on how to help staff provide high quality care to clients and families.

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## **1. INTRODUCTION**

### **1.1 Literature search procedure**

My past knowledge of working in dementia care led me to initially seek out the work of Tom Kitwood, the Bradford Dementia Group and Linda Clare. These sources provided me with a useful starting point in finding other relevant literature. In addition, conversations with people in the field such as Alisoun Milne directed me to two up to date references in this area: Mental Health and Care Homes (Denning and Milne, 2011) and Excellence in Dementia Care (Downs and Bowers, 2010).

Articles were predominantly searched through the electronic database Science Direct. In all cases search terms included the term dementia in conjunction with: biographical (532 found and first 100 reviewed), life history (27,030 found and first 100 reviewed), staff relationship (8,124 found and 100 reviewed), knowing person (2,462 found and 50 reviewed), staff and autobiographical (210 found, 50 reviewed). These results were found in August 2011. Prior to this (October 2010) and more recently (February 2012) the term dementia was combined with: identity, awareness, psychosocial approaches, life story, reminiscence and care homes. No restriction was placed on the search of criteria in terms of dates, as it was recognised that the literature in dementia care particularly around life story and identity is largely from the last 20 years. In my search strategy I was particularly interested in searching for research papers which included people with dementia themselves, aware that their voice is crucial but rarely heard. Search strategies further included scanning reference lists of relevant chapters and articles to further reading.

In addition, information was drawn from the websites of well known organisations such as the Alzheimer's Society, from recorded conferences online and from a conference I attended in July 2011 on 'challenges to identity and personhood and mental health care'.

## **1.2 What is 'dementia'?**

### 1.2.1 Definition

In medical terms, dementia is conceived as a group of syndromes, the most common of which are Alzheimer's Disease (AD) and Vascular Dementia (VD). Other types include 'mixed dementia' (usually a mixture of AD and VD dementia) and less common types including Lewy body dementia, frontal-temporal dementia and dementia in Parkinson's disease.

Although there are differences in each individual's presentation, all syndromes are characterised by progressive decline in cognition of sufficient severity for the dementia to interfere with social and/or occupational functioning (Stephen and Brayne, 2010). Dementia can affect areas such as memory, language, personality, behaviour, planning, organising, judgement and social skills. Having difficulties in one or several of these areas has an impact on an individual's day-to-day life. For example, difficulties in word finding can result in frustration for the person in making themselves understood and this can also be difficult for other people in their environment. Relatives or carers supporting individuals with dementia can find these changes difficult to manage, which can have implications for their wellbeing as well as for the person with dementia.

### 1.2.2 The political context

With an expanding ageing population and the incidence of dementia being positively associated with increasing age, the proportion of individuals experiencing dementia is likely to continue to rise. *The National Dementia Strategy* (DoH, 2009a), which aims to improve dementia care services, indicates that there are 700,000 people in the UK with dementia and this is likely to double to 1.4 million in the next 30 years thereby increasing health costs from £17 billion a year to £50 billion.

Three steps are highlighted within the strategy to improve the quality of life for individuals with dementia and their carers: to increase knowledge about dementia and address the stigma associated with dementia; to facilitate diagnosis of dementia to thereby address people's needs earlier on; and lastly to develop

services which are responsive to the changing needs of people with dementia over time. Other additional policy documents - Shaping the Future of Care Together (HM Government, 2009) and Building a National Care Service (HM Government, 2010) - propose that a reform in care and support for adults in England is required to promote better health as people get older, in conjunction with managing the economic challenges of the cost of care.

There is evidence that staying in your own home, particularly with a diagnosis of dementia, is more beneficial in terms of wellbeing enabling continuity. In Kent six intermediate care teams have developed since 2007 aimed to support individuals with dementia to live 'in the least restrictive and/or most appropriate setting, preferably one of their choosing' with promising outcomes (Culverwell and Milne, 2010). Keeping people in their own homes is high on the agenda to help manage costs to the government and personal financial costs to the individual and their family (HM Government, 2010). Keeping people in their own homes has financial benefits but most importantly prevents what can be a distressing experience for the individual and their family. Indeed, a lot of moves/moving for people with dementia has been recognised as leading to deterioration. However, the emphasis on families as the people best placed to care can be idealised and may be exaggerated by the negative press that often surrounds care homes.

### **1.3 Different perspectives on dementia**

#### **1.3.1 A medical model approach**

Traditionally, the medical approach to understanding dementia, which defines different types of dementia and corresponding symptoms, focuses on progressive loss and deficits, describing speech being 'meaningless' and memories 'defective' (Beard, 2004). A medical approach has been argued to be reductionist and it may be considered that such ideas have invited low expectations of individuals' abilities (Cohen-Mansfield, Golander, and Arnhem, 2000). Hutchinson, Leger-Krall and Skodol-Wilson's (1997) research indicated that when diagnosing dementia, physicians reported to clients' partners that 'there was nothing to do'. Such views may affect practice.

A medical approach is often accompanied by the view that a person's presentation is directly caused by brain damage. This belief can lead to a person's behaviour being interpreted as a part of dementia rather than a communication, 'rendering their actions meaningless' (Bender and Cheston, 1997). Research suggests that when time is spent getting to know the person and their life story that their 'behaviour' is understandable (e.g. Stokes, 2000, 2008). This has implications for how individuals are supported and, therefore for care practice. One's understanding of dementia is likely to make a big difference to interactions with an individual with dementia.

Although a medical definition could be argued as helpful in enabling access to treatment, such as medication for AD, this understanding alone seems restrictive. A belief that the way in which people with dementia present results from neurological changes has implications for what research is funded and which treatments are supported in terms of research and practice. This has led to medical treatments being used in an attempt to reduce 'symptoms' - often those that are challenging or distressing to those caring for the person. The prescription of antipsychotics for people with dementia is often used to 'treat' behavioural and psychological symptoms of dementia, particularly when the person or others around them are deemed by others to be at risk and/or distressed. At some point, 90% of people with dementia experience symptoms such as restlessness, shouting, aggression and loss of inhibitions (Alzheimer's Society, 2008). Yet antipsychotic medication is not licensed to treat dementia.

There has been increasing concern regarding the prescription of antipsychotics for people with dementia, in terms of the frequency of their use and their sometimes being detrimental to people's quality of life, potentially having adverse effects on cognitive ability, and in more extreme cases, resulting in death (McShane, Keene, Gedling, Fairburn and Hope, 1997). Side effects can include sedation (often observed in care homes), dizziness, unsteadiness leading to increased risk of falls, parkinsonism (tremors and rigidity), social withdrawal and cognitive decline (Alzheimer's Society, 2008, 2011a, 2011b, 2011c). All of these effects can have an impact on individuals' psychological wellbeing, for example,

affecting people's confidence and self-esteem; such psychological changes can often be attributed to the person's age and/or dementia.

There is an important question of who these medications are being prescribed for, as they do not always seem to be in the best interests of the person with dementia. Recent publications and documentaries have raised awareness regarding the use of medication in care homes and some homes are now striving to work with a philosophy of not prescribing medication. Alldred, Petty, Bowie, Zermansky and Raynor (2007) suggest one third of people with dementia in a care home take antipsychotic medication. Yet there is evidence to suggest alternative strategies are effective (Ballard et al., 2001; James and Stephenson, 2007).

There is increasing recognition by carers, organisations and academics that medication has been overused in older people and dementia care, which has led to several reviews. A report by Professor Banerjee for the Department of Health (DoH, 2009b) found that over two thirds of the 180,000 prescriptions for people with dementia in the UK were inappropriate. The All Party Parliamentary Group on Dementia (APPG, 2008) supported this, estimating 105,000 people to have been prescribed antipsychotics inappropriately. Reducing antipsychotics is now a national priority in England (DoH, 2009b) with an aim to improve treatment and care in reducing their use.

In addition, there is now an increased emphasis on so called 'challenging behaviour' being a communication of unmet need. The APPG report (2008) highlighted this and drew attention to thinking about the context of care. Their findings indicated that antipsychotic drugs tended to be administered to address factors that were not actually a direct result of dementia. They found staff were not necessarily aware that restlessness may indicate an unmet need such as boredom or pain rather than being caused by dementia. This would suggest a treatment approach with the system may be more helpful than internalising the problem as part of the person. Training and support for staff has been found to

be useful in using alternatives to medication to manage 'challenging behaviour' (Fossey et al., 2006).

In recent years there has been increasing interest, investment and support in psychosocial interventions for individuals with dementia and this has been recommended by National Institute for Health and Clinical Excellence – Social Care Institute for Excellence guidance (NICE-SCIE; 2006) and the National Institute of Health Research (NIHR; Iliffe et al., 2008).

### 1.3.2 A social model approach

The social disability model (Gillard, Means, Beattie and Darker-White, 2005) offers an alternative way of understanding dementia which highlights the importance of context in understanding individuals with dementia. It offers a way forward in addressing some of the limitations of the medical approach, particularly in relation to the negative perceptions and stigma around dementia.

The stigma associated with a diagnosis of dementia is highlighted by the reluctance of many to seek help and the drive by policy to address this. Husband (2009) suggests individuals try to hide their difficulties, evidenced by not telling people close to them due to fear of response and, perhaps, as a defence to protect their sense of self as well as possible fear of what may happen next. This behaviour may well be exacerbated by the discourses in society. Post (2000) suggests we live in a hypercognitive society where intellect and productivity are very highly valued and Kontos (2004) suggests we should look at more complex and plural understandings of the selfhood. What is valued in society will inevitably have an effect on how people are viewed by others. The discourses that surround old age vary between and within cultures - some of these are negative, where older people can be viewed as being less able, less productive and, therefore, less valued. MacRae, (2011) suggests that loss of cognitive abilities can lead to assumption of a loss of self. Milne (2010) suggests that the stigma often experienced with old age compounds that surrounding a diagnosis of dementia, making it even more difficult for the individual, and leading to further marginalisation. Discourses around loss of ability, poor quality of life

and poor care homes can understandably lead people to hide their difficulties, perhaps reflecting resilience of the individual but, more importantly, highlighting the negative effect of these discourses and the need for change to reduce fear. Ryan, Bannister and Anas (2009) suggest that people with a diagnosis of dementia may experience impoverished interactions as a result of such views.

Addressing stigma is one strategy to break down barriers to help-seeking in order to increase early diagnosis, provide treatment and support to the person and their family. Stigma can increase the distress experienced by the person, exacerbating their difficulties (Thornicroft, 2006). The practice of labelling individuals with a mental illness has often been documented as having negative consequences for the individual, with the label seemingly overriding and taking in all other personal attributes and qualities of the person (Goffman, 1963). As already indicated, reducing stigma and discrimination are key objectives of the National Dementia Strategy (2009).

The social disability model considers how the responses of others and how an individual is positioned, can have an effect on one's wellbeing; it proposes that as a consequence of our thoughts and actions in society we place individuals with dementia in a certain position. Sabat (2001) argues that people act out of the context which is available to them. This suggests that our knowledge and views about dementia and the person will inevitably shape our interactions and, therefore, the context available to them, so that opportunities to flourish may be limited. This highlights the potential interplay between individuals' knowledge and actions.

It is only more recently that research exploring individuals' experiences of dementia has been sought, which is reflective of the attempt to move away from these negative discourses that in the past assumed individuals as not capable or important in giving their view. Research has suggested a need to reframe dementia. Both Beard, Knauss and Moyer's (2009) textual analysis by individuals with dementia, and Langdon, Eagle and Warner's (2007) interviews of people with dementia found that, although people tried to manage and

incorporate the changes in their lives, there were challenges as a result of the negative discourses in society, which had implications for important aspects of their lives, such as sustaining relationships. Comments from people with dementia have included negative perceptions such as ‘nobody really wants to talk to you any longer’ (Henderson, 1998: 18) and beliefs that people fear coming close to them (Truscott, 2004).

Medical and societal discourses have notably had an effect on care practice over time and so perhaps it is not surprising that there has been neglect, abuse and social exclusion of individuals diagnosed with dementia. Assumptions about these individuals have perhaps hindered our ability to consider approaches other than ‘chemical restraint’ earlier. Milne (2010) highlights that the assumption that dementia is part of aging means it has been viewed as unsuitable to intervention in the past; again, such views may have got in the way of developing psychosocial interventions. The possibility that people with dementia can experience good quality of life has perhaps been unthinkable (Livingstone, Cooper, Woods, Milne, and Katona, 2008).

Cantley and Bowes (2004) suggest that it is our approach to people with dementia, the language used to describe people, and the environments we create that disempower, dehumanize, marginalise and stigmatize – not the condition itself; suggesting that social context may affect one’s experience of dementia in addition to, and sometimes more than, the neurological changes associated with the diagnosis. This is supported by Kitwood (1997), who proposed the notion of ‘malignant social psychology’ to describe this style of interaction and relationship with the person with dementia that had the effect of diminishing their personhood. This relates to Sabat’s (2001) ideas and emphasises the importance of social feedback. Relationships, therefore, seem key in supporting individuals with dementia and perhaps offer an approach which allows for the possibility of rehabilitation rather than decline. Kitwood emphasised the importance of relationships and this was influential to the concept of ‘person-centred care’.



Since Kitwood's (1997) ideas of 'social malignant psychology' and 'person-centred care' there has been increasing interest and research into reconceptualising dementia.

## **1.4 Finding the person in dementia**

### **1.4.1 Person-centred care**

Kitwood (1997) emphasised the idea of 'personhood', a term that he acknowledged had been used in many and various ways, including to describe: the place of an individual within a social group; the performance of given roles; the integrity, continuity and stability of the sense of self. He used the term to describe a standing or status that is bestowed upon one human being, by respect and trust. He emphasised the importance of focusing on the PERSON rather than the dementia.

Kitwood's (1997) perception of person-centred care was the preservation of 'personhood'. Subsequent to his definition of person-centred care there have been a number of different definitions used. In a review of these, Brooker (2004) suggested four essential elements: 1) care that values people regardless of their difficulties; 2) care that recognises uniqueness and individuality; 3) a position of taking the perspective of the person with dementia; and 4) in order to help people maintain relationships with others, supportive social psychology is required - this being likened to a set of ramps and wheelchairs for those with physical impairment.

The concept of personhood has challenged assumptions that the person with dementia has no sense of self (Downs, 1997).

### **1.4.2 The person: 'identity' and 'awareness'**

The concepts of 'self' and 'identity' have received increased attention (Clare, 2003; 2004). However, these terms have been recognised as taking on different meanings and this is highlighted in a recent systematic review which explores the impact of dementia on self and identity (Caddell and Clare, 2010).

One definition of identity has suggested it encompasses a set of beliefs one holds about oneself (Brehm, Kassin and Fein, 2002). A stable self shaped through early interactions and a set of fluid selves have been proposed, which comprise one's social identity. This is suggested to derive from one's context, which may shift over time and between circumstances.

A social theory of identity, social constructionism, suggests that an individual communicates varying personae to others (Sabat and Harre, 1992). Therefore, the reactions of others help us to learn about ourselves (Gergen, 1971), which is likely to have implications for our wellbeing. This highlights the importance of tackling the stigma that often comes with old age and dementia, as discussed above. Language, social patterns and relationships are key in influencing how people experience themselves.

The question of whether 'identity' is present in the person with a label of dementia, and whether and how it can be maintained, is increasingly being explored in the literature, though methodological approaches have varied depending on the definition used.

A growing number of studies have suggested identity is present in individuals in the early stages of dementia and that they are able to meaningfully interact, and a few studies have found this to be the case with individuals in the later stages of the condition (Caddell and Clare, 2010; Clare, Rowlands, Bruce, Surr and Downs, 2008a; Hyden and Orulv, 2009).

Twigg's (2010) research is an example which challenges us to move away from the assumption that verbal communication reflects whether identity is present. Through Twigg's observations, clothing was found to remain significant to people in maintaining their identity and offered them a sense of agency. Twigg discusses the notion of embodied selfhood, drawing attention to the social characteristics below the threshold of cognition at a pre-reflexive level, and suggests that identity presents in habitual gestures and actions and is still present despite neurological damage. This perspective further challenges the negative accounts of dementia,

again highlighting the role of contextual factors in influencing the expression of awareness (Clare, 2004; Clare, Markova, Roth, and Morris, 2011)

Hubbard, Cook, Tester and Downs (2002) propose that non-verbal behaviour can be utilised by carers to preserve identity. Increasingly, research on communication is including people with dementia themselves and focussing on facilitation of identity preservation, for example with the use of intensive interaction and talking mats (Murphy, Oliver and Cox, 2010). This will hopefully challenge practices where carers do not spend time communicating with people because they assume they cannot communicate (Ekman, Norberg, Viitanen and Winbald, 1991) due to difficulties with language, which can be made more difficult due to sensory difficulties. Bearing in mind non-verbal communication is thought to comprise the greater part of the message, helping others to attend to this is likely to have positive results.

#### 1.4.3 The voice of the person with dementia

In the research literature there has been a poor representation of hearing from people with dementia themselves. Reasons for this include physical and cognitive difficulties, barriers to consent, difficulties in communication and questions around the validity of the individual's response (Bowers et al., 2009; Milne, 2010). This has resulted in carers perspectives overshadowing their voice (Wilkinson, 2002).

However, where individuals have been involved they have been able to describe their situation and retain identity which challenges assumptions. They have also stated that they want their living situation improved (Clare, Bruce, Surr, and Downs, 2008b). To date, research with individuals with dementia suggest residents' priorities differ from carers ideas which focus more on functional and cognitive deficits (Milne, 2011). Indeed Bowers et al.'s, (2009) research with residents, some of whom had advanced dementia indicated the following as important to quality of life: Personal identity and self esteem, meaningful

relationships, home and personal surroundings, meaningful and daily community life, personalised care and support and personal control and autonomy.

It is not just the research context where peoples' voices need to be heard but perhaps more importantly developing communication skills to facilitate discussion and listen on a day to day basis. Runnicles (2011) proposes that hearing the persons' voice through knowing their life history enables carers to understand many of their behaviours which could otherwise be viewed as unpredictable.

### **1.5 Psychosocial approaches**

In view of the concept of person-centred care and personhood a number of psychosocial approaches have been suggested which have showed some initial promising findings in facilitating the maintenance of identity and seem more in line with what people with dementia are asking for (Clare et al., 2008b). There is increasing evidence that psychosocial approaches compare well to drug treatments to maintain quality of life and are free from the adverse side effects of medication (Bruce and Schweitzer, 2010).

Several systematic reviews looking at the effectiveness of psychosocial interventions have been conducted, with some attention paid to what interventions are most appropriate at each stage of dementia (Bates, Boote and Beverley, 2004; Boote, Lewin, Beverley and Bates, 2006; Woods and Clare 2008). However, there are problems with many of the studies undertaken to evaluate psychosocial approaches, with poor design and small sample sizes, for example, Boote's systematic review of five psychosocial interventions only drew on a total of six studies, all of which took place in group settings. Also there seems to be a focus on cognitive functioning as an outcome measure, which may not reflect others' ideas of what is important and may not be in line with what clients want.

Psychosocial approaches have included multi sensory stimulation, music therapy, cognitive stimulation therapy and biographical approaches. For example, reminiscence and Life Story Work (LSW), in particular, can help people to

maintain their identity and find meaningful activities. Identity has been thought to be closely linked to self esteem and quality of life (Davies, 2001; McKee et al., 2005). Brodaty, Green, and Goschera (2003) suggest that these interventions are most effective when the family and the person are included in the work, highlighting the importance of the interpersonal aspect.

#### 1.5.1 Multi-sensory stimulation

Multi-sensory stimulation uses stimuli such as light, sound and tactile objects to increase opportunity for communication. Baker et al. (1997) and Van Weert, van Dulmen, Spreeuwenberg, Ribbie and Bensing (2005) suggest associated improvements in mood and behaviour with its use.

#### 1.5.2 Music therapy

Music therapy includes playing and listening to music. It can be structured or unstructured. It has been suggested as an option for the treatment of behavioural, social, cognitive and emotional problems of people with dementia. However, a Cochrane review (Vink, Birks, Bruinsma and Scholten, 2004) suggested that due to poor methodological quality it is difficult to draw useful conclusions.

#### 1.5.3 Cognitive stimulation therapy

Cognitive stimulation therapy (CST) draws on reality orientation, reminiscence and multi sensory stimulation. It utilises peoples preserved abilities and reinforces autobiographical memory, which can enhance subjective feelings of well being (Moniz-Cook, 2008). Benefits have been demonstrated in cognition and associated improvements in quality of life for individuals with mild to moderate dementia, but it is felt unlikely to benefit individuals in later stages of dementia.

#### 1.5.4 Reminiscence therapy

Reminiscence therapy involves the discussion of past experiences, individually or in a group, which may utilise familiar objects. A number of functions for reminiscence have been suggested, for example, to retain autobiographical memory, maintain a positive sense of self, to promote communication and to build relationships (Moniz-Cook, 2008).

Although there are promising results from reminiscence therapy, types of this work and methods vary. Woods, Spector, Jones, Orrell and Davies (2005), who reviewed studies in this area, stated that better designed trials are needed to draw conclusions.

Woods and Clare (2008) argues that reminiscence gives the message that the person is respected, valued, interested and that, if others value them, this helps them be positive about themselves.

#### 1.5.5 Life story work

LSW shares many principles with reminiscence. It involves looking back on, gathering information about and recording a person's past (Batson, Thorne and Peak, 2002). A book can be produced, which can help with maintaining identity and can be used to facilitate individualised care plans and understand the person. More detail on this approach is described later on in this section.

Thought needs to be given to consider how research in the area of psychosocial interventions is carried out and how outcomes are measured perhaps using 'practice based evidence' rather than 'evidence based practice'. We need to consider what people with dementia are telling us and, therefore, consider what we measure and how when evaluating outcomes so that they are in line with their hopes.

## **1.6 Dementia in care homes**

Objective 11 of the National Dementia Strategy is focused on improving care for people with dementia in care homes.

The term 'care home' has been used to encompass nursing homes and residential homes and will be used as such throughout this document. Care homes are provided either by local authorities, the National Health Service (NHS), voluntary organisations or private companies. In the United Kingdom 5% of individuals over 65 live in a care home and this increases with age to 16.2% for individuals over the age of 85 years (Laing and Buisson, 2009). It has been estimated that two thirds of residents have dementia; however, not all care homes provide specialist dementia care (Alzheimer's Society, 2007; Matthews and Denning, 2002). Services for people whose primary health problem is dementia have only recently begun to be developed (Marshall, 2005).

While some people with dementia may be able to stay at home, many move to a care home. Bannister, Ballard, Lana, Fairbairn and Wilcock (1998) suggested that the two most common contributory factors to admission are the severity of cognitive impairment and the reduced use of active coping strategies by carers (i.e., if active steps are not taken by the carer to manage the behaviour), which were associated with psychiatric morbidity in carers. When carers find it difficult to cope, their distress may contribute to distressed behaviour in the person with dementia (Woods, 2004). Research has suggested behavioural problems are also influential to admission (O'Donnell, Drachman, Barnes, Petersen, Swearer and Lew, 1992). Often the individual who is looking after the person with dementia may be elderly themselves and, therefore be at increased risk of health problems.

Davies and Nolan (2003) indicate that the decision to move can be distressing for both the person with dementia and the family. For the person with dementia, moving has been shown to impact negatively on their abilities and well being (Fossey, 2010), with a deterioration in role-identity (Cohen-Mansfield et al., 2000). The experience of decision making and the transition can have a big

impact on the person and significant others. However, if staff understand what the move means for the person and their family, this can help staff to support and maintain relationships (Fossey, 2010).

Warner, Milne and Peet (2010) suggest there is limited consensus on what factors affect quality of life in care homes, but that it is likely to be influenced by external and internal issues. Factors outside the control of individual homes include the regulatory and competitive environment. Attitudes, behaviours and interactions by staff with residents are mediating factors between aspects of the care environment (facilities, management, workforce) and wellbeing and quality of life of residents (Gage, Knibb, Evans, Williams, Rickman and Bryan, 2009).

It has been suggested that the homes that provide good care focus on leadership and staff management, staff training and development, and person-centred care planning; they provide a safe environment and purposeful activities that relate to individual preferences. The National Dementia Strategy aims to improve the status and image of work with dementia and challenge the secondary stigmas often associated with it (Brodaty et al., 2003). Staff are still undervalued, experience burnout, stress and low levels of staffing, which has a direct effect on residents. A statistically significant relationship between training and wellbeing has been reported (Commission for Social Care Inspection: CSCI, 2008).

#### 1.6.1 Communication and relationships

Twenty years ago it was felt that dementia resulted in a loss of communication and that meaningful relationships with others were not possible (Kitwood, 1997). However, the recognition of psychological and social understandings have challenged this, as has the research on identity (as discussed). Bearing in mind Kitwood's concept of personhood, this suggests we are persons when we are in relationship with and recognised by others and this applies to the person and staff, therefore, communication is central to personhood.

Although individuals with dementia have progressively more difficulties in communication, this is not necessarily just a result of changes in the brain but the



environment or 'malignant social psychology'. For example, Ekman et al. (1991) found that nurses spent less time communicating with individuals with severe dementia, as they perceived them unable to communicate. In addition, anxiety and depression, which could be the result of the environment are likely to lead to changes in one's communication. Research suggests individuals with increased cognitive impairment are more likely to be isolated and disengaged (Hubbard, Tester and Downs, 2003).

Bond (1999) proposes that verbal communication is less important, rather, it is the emotional and empathetic interaction that is required for good dementia care. Less attention has been given to non-verbal communication but a move towards this could be key. Hubbard et al. (2002) emphasise that the ability to recognise non-verbal communication and work with it can help preserve identity, thereby increasing quality of life.

Hancock, Woods, Challis and Orrell (2006) suggest that environmental and physical health needs tend to be met in care homes, but mental health needs and social needs can be neglected and lead to psychological problems and reduced quality of life. Despite attention being drawn to improving care in care homes over recent years, there is still a long way to go. For example, Ice's (2002) research looked at how nursing home residents spent their day and suggested that, 25 years on, although a high standard of care was reported at the home where the research took place, residents spent 65% of their time doing nothing and only 12% in activities. Furthermore, the Home from Home report by the Alzheimer's Society (2007) found that over a six hour period of observation, two minutes was spent interacting with staff; a concern also expressed by carers. This is despite the increasing emphasis on the importance of opportunities for individuals, for example, in activity, which can be helpful in building relationships and for mental wellbeing.

When speaking with staff, Ward, Vass, Aggarwal, Garfield and Cybyk (2005) found there was a tension between staff being aware of opportunities to speak with residents and feeling limited due to their workload and how tasks were organised. This highlights the role of the organisation and also the 'invisible work

load' of managing staff's own and clients emotions, for which there was found to be little opportunity to share or reflect (Ward, Vass, Holland and Peace, 2006).

The notion that knowing about an individual can help build a relationship with them is important with regards to one's wellbeing and Werezak and Morgan (2003) and Zgola (1999) suggest that the relationships that the person has are the most important foundation for wellbeing. This was supported by CSCI in 2008, when observing the interactions of 424 people using an observational process (the Short Observational Framework for Inspection-SOFI).

The research to date, including research with people with dementia themselves suggests they want care to be improved. Clare et al. (2008b) makes a number of recommendations based on her interviews with individuals with dementia in residential care, including giving more support to maintain role identities, engaging with residents life stories and past memories, facilitating opportunities to continue social roles and to feel helpful and useful.

### **1.7 Using life story work in care homes**

For care to be person-centred, having an understanding of a person's life history has been suggested as necessary, to know where individuals have come from in order to understand who they are now (Bruce and Schweitzer, 2010).

As outlined earlier, when used as a book, LSW provides a tangible and valuable tool to help the person hold on to a positive sense of self (for example, through past accomplishments) and help professionals deliver person-centred care (Batson et al., 2002).

Research suggests this work can be valuable with people with dementia, family and carers (Batson et al., 2002; Bender, Bauckham and Norris, 1999). It can: alter how people are perceived, helping staff see beyond the diagnostic label; help with communication, for example, understanding the meaning behind what people say or do, thereby helping understand and manage 'challenging behaviours' (Stokes, 2008). It can help to meet emotional needs, and provide

ideas for occupation (McKeown, Clarke, Ingleton, Ryan and Repper, 2010) which Marshall and Hutchinson (2001) argue can make a positive contribution to increasing social interaction. LSW has therefore helped people form and maintain relationships, creating warmer feelings towards the person and a better understanding of the individual with dementia (Pietrukowicz and Johnson, 1991).

MacRae's (2011) interviews with individuals with dementia highlighted the importance of others in helping the person construct and maintain identity. A sense of self was dependent on the response of others rather than the disease - a finding that has important implications for care home settings. This highlights the importance of providing positive identity-affirming interactions.

McKeown et al. (2010) explored the use of LSW with people with dementia to see how it was understood, experienced and developed in practice and how it affected the delivery and outcomes of care. Pride and enjoyment were recognised through using LSW. An example of this was where a staff member commented on a person's achievements and the person responded through non-verbal behaviour, 'shuffling her clothes', which seemed to suggest pride. Bearing in mind the threats dementia can bring to people, for example, prolonged grief for changing or lost relationships, increasing social isolation, feelings of subjective burden, stress and exhaustion (Bruce, 1997), LSW can assist carers to hold onto and celebrate good times and may help restore relationships and facilitate new ones. Batson et al. (2002) discussed one instance where a person was admitted to hospital and staff on the ward reported that LSW had helped them deliver a person-centred approach more quickly. This illustrates some of the benefits of sharing information, including the potential to improve wellbeing, sense of self, esteem and empowerment

Baldwin (2008) suggests that the more one knows about the person with dementia, the more can be followed up on which helps us to maintain connections with the 'touchstones' that are familiar in people's lives (Brooker, 2011). Ignoring life history, Kenyon (1996) suggests, poses greater risks than working with it. However, Kenyon emphasises the need for respect and

negotiated consent. It seems important to consider and ask what people would want others to know and what they would prefer to be kept private.

Results to date from LSW demonstrate the positive impact it can have on promoting care practice (Surr, 2006). However, quality research into LSW is scarce (McKeown, Clarke and Repper, 2006) and Gibson (2007) suggests this continues to be a rather unexplored resource and we are yet to use it effectively (Bruce and Schweitzer, 2010). In considering implementation of LSW, McKeown et al.'s (2010) research suggests that taking a planned approach to implementation does not always work and prevents LSW being sustained in practice. Brooker (2010) has also highlighted the difficulty in implementation of LSW and staff in Batson et al.'s (2002) research suggested finding time was a challenge.

## **1.8 Rationale for current research**

Further research is needed to facilitate our understanding of how we can best work with individuals with dementia in care home settings. Considering the literature, the policy documented and, most importantly, our (albeit incomplete) understanding of what people with dementia themselves want, psychosocial interventions seem a priority.

It seems clear that drawing on people's life histories supports identity and improves wellbeing. It is therefore crucial to understand how we can maximise the use of life histories in working with people with dementia. Brooker (2011) indicates that often little is known about people in care homes and Hetzberg and Ekman (2000) suggest lack of knowledge about the person's needs and life history may be due to limited communication between staff and families.

In addition, the literature suggests that social and historical narratives around dementia (for example, that individuals may not be aware), may hinder the collection of information about individuals, or use of life history in working with them, as this process may be viewed as pointless. It seems important to hear from staff what their view on the utility of life history is, especially as views

change over time, as reflected by policy and the move towards person-centred care.

Person-centred ideas are not new but these have been difficult to maintain in practice (Hoe, Hancock, Livingstone and Orrell, 2006; Alzheimer's Society, 2007). McKeown et al. (2010) suggest that LSW has the potential to improve person-centred practice. However, the challenge of implementing LSW and sustaining it in practice raises the question of what is possible in care homes. Viewing LSW as a job to do and/or a job completed is not likely to sustain the positive effects. Brooker (2010) suggests drawing on life history is about the interaction and relationships that occur, enhancing identity, attachment and occupation; therefore it is how life history is used that is crucial.

Although some research has been done on the effects of LSW after a structured intervention has been delivered, there has been little investigation into what happens day-to-day in care homes in order to utilise life history. There is a need to learn if and how this happens in the context of a care home setting. Staff on the ground seem best placed to provide information about what happens, what works and what is possible.

#### 1.8.1 Aims

The aims of this research were:

- To understand the process and experience of a person with dementia coming into a care home from the perspective of care staff
- To explore:
  - 1) What information staff know about a person and their history
  - 2) Whether there is particular information about a person that is useful to know
  - 3) How this information is used in care practice in a way that has an impact over time

### 1.8.2 Research questions

The research questions were:

- 1) What are staff's experiences of getting to know individuals with dementia?  
and
- 2) What helps/hinders opportunities to get to know an individual in a care home setting?

## **2. METHOD**

### **2.1 Epistemological position**

A critical realist epistemological position was taken for this study, maintaining focus on the data and 'reality' whilst considering the limits on 'reality'; that is, how discourses and the broader social context influence people's meanings. In other words, from this stance it is assumed that real events occur but that 'each person experiences and gives meaning to events in light of his or her own biography or experiences' (Corbin and Strauss, 2008: p.10). Therefore a critical realist epistemology recognises the subjective element in knowledge production (Willig, 2008).

I took the view 'that concepts and theories are constructed by researchers, out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences, both to the researcher and themselves' (Corbin and Strauss 2008: p.10). Out of these multiple constructions, analysts highlight patterns. There may be a diversity of potential interpretations of the data, and despite the epistemological approach, one interpretation cannot be considered the only appropriate one. This framework guided the research process.

Bearing this in mind and the importance of transparency particularly in qualitative research I recognise it is important to consider what I might bring to the research context and to consider how this might affect the analysis. My interest in improving dementia care was informed by my previous experience working in a care home prior to training and I have tried to keep in mind my assumptions and reflect on these throughout the research process.

It is not possible for the researcher to separate themselves from the research and analysis. However, by clearly stating this limitation, the reader can be mindful of this and consider the results with respect to the researchers background. Please refer to the critical review for further discussion.

## **2.2 Thematic analysis**

For this study, Thematic Analysis (TA) was informed by a critical realist framework. Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA) were not felt to be appropriate. GT was considered to be constraining rather than enhancing the area of study, which was considered explorative at this stage. IPA was not considered appropriate as the interview questions were not confined to people's accounts of their own subjective experiences. TA also allowed flexibility when considering theoretical position and framework.

TA facilitates the identification and analysis of patterns of meaning across a set of data (Braun and Clarke, 2006). An inductive approach was used due to the explorative nature of the study, i.e. the themes identified were strongly based on the data generated from participants' experiences.

Though rarely acknowledged and specified as a method in the past, TA is widely used and there is increasing reference to this method in the literature. Braun and Clarke's (2006) paper is used as a key reference when researchers have been explicit about their procedure of analysis. More recently, Joffe has dedicated a chapter in Harper (2012) to TA, perhaps reflecting increasing interest in making these methods more explicit and useable for researchers.

## **2.3 Ethical approval and confidentiality**

Ethical approval for the running of this project was sought and approved by The Ethics Committee of the School of Psychology, University of East London (see appendix A).

Confidentiality was highlighted verbally and in written format using the information sheet (appendix B) before commencing the interview, as well as forming part of the consent form (appendix C). Interviews and transcripts, were anonymised by assigning a number to name of site and person, and pseudonyms to names mentioned in the interview.



All information from staff was accessed only by the researcher and only anonymised data shared with supervisors. Data was kept in a locked cabinet and password protected to computer. Materials will be kept in a locked cupboard until results have been written up. Paper will be shredded and recorded tapes erased. Electronic data will be saved for up to 5 years.

## **2.4 Participants**

Nine participants were recruited across three sites based in the South of England.

### 2.4.1 Description of homes

#### *Site one*

A private family run residential and nursing home for 54 individuals with mental health difficulties and/or a diagnosis of dementia. This home has been in operation since 1988 and aims to address health, emotional, social and psychological needs for each individual client and to enable clients to live an independent normal and satisfying life.

#### *Site two*

A private, family run residential and nursing home for 56 individuals with mental health difficulties and/or a diagnosis of dementia. This home has been in operation since 1993, stating it aims to respond to individual needs.

#### *Site three*

A nursing home and dementia care home separated into units including: brain injury, early/middle/late stages of dementia with 78 clients. This home has worked with the organisation Dementia Care Matters (DCM), which focuses on person centred and relationship centred care, with a key emphasis on attending to feelings and achieving emotional connection, with the view that this is at the heart of being person centred. Examples include: accepting a person's reality makes sense, being honest and addressing outdated models of care, attending to staff's emotions and moving away from detached management styles which lacked emotional connection and created task based care.

One participant was recruited from site one - the pilot interview (two did not meet the screening criteria), five participants from site two and three participants from site three. Staff were aged 18-54 years old (mean 40.5). Six were female and three were male; five were British and four from other countries; for six participants, English was their first language, and for three their second. Participants had between three and 25 years' experience of working in dementia care (mean 9.8). Five were care assistants, two were managers of units within the home with a care assistant background, two were nurses - one of whom was in a managerial role. Seven of the nine participants had worked in the caring profession prior to their current job.

The pilot interview was included in the analysis as the data elicited remained in line with the research questions.

See *Table one* for descriptive information for each participant.

*Table one*

Site number	Pseudonym	Age	Gender	Ethnicity	First language	Years in dementia care	Prior experience and roles held	Current role
1	Lorna	54	Female	British	English	25	Care Assistant (NVQ 2 & 3)	Senior Care Assistant
2	Emma	18	Female	British	English	3	Care Assistant	Care Assistant
2	James	39	Male	British	English	8	Care Assistant, Nursing roles	Nurse Manager
2	Anu	32	Female	Indian	English (2 <sup>nd</sup> language)	3	Nurse (intensive care)	Nurse
2	Daniel	53	Male	British	English	12	Hospital LD and MH Senior Nurse, LD and MH Care Assistant	Care Assistant - predominantly night staff
2	Dorina	42	Female	Romanian	English (2 <sup>nd</sup> language)	3	Administrator	Care Assistant
3	Kate	37	Female	British	English	17	Night carer, day carer (both-nursing home), carer in community	Head of Unit
3	Rachel	52	Female	South African	English	10	Care Assistant/support worker (Alzheimer's Society)	Head of Unit
3	Patrick	38	Male	Nigerian	English (2 <sup>nd</sup> language)	8	Security, Sainsbury's, Carer and Senior Carer	Senior Carer

## **2.5 Materials**

A standardised email/letter was written for managers who were interested in taking part, initially introducing myself and the project (see appendix D). A socio-demographic information sheet was used with each informant to gather some basic descriptive information on participants. This included: age, gender, ethnicity and country of origin, first language, years of experience working in dementia care, prior experience and roles held, and current role. This fits with a constructionist position and was collected with a view to provide more context to the material helping the reader to evaluate the range of persons and situations to which the research may hold relevance; this is recommended as good practice (Elliot, Fischer and Rennie, 1999; Smith, Flowers and Larkin, 2010).

The socio-demographic form (appendix E), information sheet and consent form were shared with the informant prior to commencing the interview. An interview schedule was used as a guide to conduct semi-structured interviews and the interviews recorded using a digital voice recorder.

### **2.5.1 Development of interview schedule**

The questions forming the interview schedule were based on my professional experience and a review of the literature, and were further developed through discussion with my supervisors who also had worked as clinical psychologists in older adult services. The schedule was also reviewed by Linda Clare and Alisoun Milne, both of whom have conducted research/reviews in the area of dementia and care homes.

A pilot interview was conducted in order to trial the interview schedule and, if necessary, to refine this following reflection and discussion with supervisors. This led to a revised interview schedule (see appendix F) including prompts and follow up questions to keep in mind, aimed at increasing understanding of the process when someone comes into the home, questions around practicalities of what happens, helps, and is possible in building relationships and sharing information as well as staff's experiences of working with people at the middle or later stages of dementia.

The aims of the questions were to ensure that all areas of interest were covered whilst allowing the informant to elaborate on their views in a relatively natural conversational way. Therefore, to gain a rich understanding from informants, it was considered important not to restrict people through closed questions but to create room to hear individual accounts in depth to facilitate understandings. However, in order to answer the research questions it was important not to drift too far from the interview schedule.

The revised semi-structured interview schedule was developed with the aim of facilitating participants' discussion regarding their experiences of, and views about, the areas being investigated. The schedule provided a guide to ensure similar questions were asked to each informant, with probes and follow-up questions. The schedule was structured in such a way that it followed the process of what occurs when first meeting an individual with dementia, through to how the relationship with a person progresses, but there was flexibility to move through this in a way that flowed with informants' responses. The prompts were not necessarily all used.

## **2.6 Procedure**

### **2.6.1 Recruitment**

Contact with the home manager and private owner of *site one* was initially made to discuss the project. This initial contact was based on my previous connection with the home, having been employed at a sister home as a care assistant thirteen years ago.

Recruitment progressed through an internet search using the following databases of residential and nursing homes for people with dementia: [www.carehome.co.uk](http://www.carehome.co.uk) (accessed August 2011). The search was based on localities accessible to the researcher, including London and the south of England. Twelve home managers were contacted by telephone and sent a follow-up email introducing myself and the project and outlining confidentiality. The information sheet and ethical

approval form were attached. I offered to meet with managers personally and/or the staff team at convenient times, such as during handovers.

The response from managers varied, there being difficulties following up contact with managers from some homes, and some managers deciding not to take part due to limitations around time and resources. This was despite it being made clear that interviews could take place outside of work.

In addition to *site one*, three of the twelve home managers approached agreed for to me to meet with them to inform them further about the research and discuss recruitment of staff. Two of the three visits led to recruitment; at the third home there were no interviews due to lack of interest from the management.

An initial meeting with the manager followed by attendance at two staff team meetings took place at *site one* and *site two* with the aim of increasing opportunities to meet staff. A notice was put up at the homes involved in the research and in the communication book for staff, thereby increasing accessibility to staff who may not have been present at meetings, and to give those who *were* present the choice to sign up following the meeting. Staff were offered the opportunity to meet inside or outside of work time and premises as it was recognised that staff may feel more comfortable to talk about work-related issues away from their working environment. Managers had given their consent to staff taking part during working hours in a spare room. Staff either approached me after the meetings or later contacted me or the manager to arrange an interview.

For *site three*, a meeting with staff was proposed to maintain continuity, however, the manager stated a preference to me coming in on an agreed day and informally asking staff if they would like to take part. Staff were approached informally and requested if they would be interested in taking part.

Screening criteria included: i) nine months of experience in working with people with dementia, to ensure participants had sufficient experience to draw on to

answer the questions and ii) a good level of English. This was shared during initial contact with the managers and at the staff meetings.

#### 2.6.2 Interviews with staff

Interviews lasted between 29 minutes and 105 minutes (mean 59 minutes). I introduced myself to participants as a trainee psychologist. At the beginning of the interview participants were shown the information sheet and confidentiality was explicitly addressed with regards to recording, transcription and publication. All participants signed a consent form.

At the beginning of the interview, to reduce anxiety and be transparent about the research process, I shared my hope with participants that the interview could be a two-sided conversation, so that although I had some questions, I would also be guided by what they brought to the interview. All interviews were recorded.

The interview schedule was used to guide questioning, but was used flexibly in order to allow the interview process to be more fluid. The interviewer took the position of active listener (Smith et al., 2010).

#### 2.6.3 Transcription

Interviews were transcribed verbatim into a word processor. As this research aimed only to examine the content of the interviews, few non-linguistic features of speech were noted (Willig, 2008). See appendix G for transcribing conventions (adapted from Banister, Burman, Parker, Taylor and Tindall (1994).

Lines were numbered and wide margins used to enable thoughts, queries and themes to be recorded and referenced. Transcripts were checked against the tapes for accuracy.

#### 2.6.4 Analysis

It was the initial analysis of the pilot interview that helped to review some of the schedule but the questions did not change considerably, therefore there was a

substantial amount of data which could still be utilised and so it formed part of the final data set with the eight other transcripts.

There were six stages in the analysis (see appendix H) and these were recursive as recommended 'where movement is back and forth as needed, throughout the phases' (Braun and Clarke, 2006: p. 86).

Initially, there was a familiarisation process with the data. At the next stage, initial coding took place, following which codes were collated into potential themes (an example of coding is illustrated in appendix I). Codes that did not reoccur were not considered thematic (Buetow, 2010). Both the recurrence and importance of individual codes were considered as Buetow (2010) proposes, this 'saliency analysis' enhances TA.

A theme was defined based on Braun and Clarke (2006: p.82) 'a theme captures something important about the data in relation to the research question' and denotes some level of patterned response or meaning within the data set. In agreement with Braun and Clarke (2006), Buetow (2010) and Joffe (2012), a higher prevalence of a pattern/theme was not equated to having more significance. The themes were reviewed to ensure the coded extracts fitted with the entire data set. Ongoing analysis to define and name the themes continued, leading to the selection of extract examples for the writing of this report

As an inductive approach was taken, the themes were strongly linked to the data themselves. Following Braun and Clarke's (2006) method for TA, the data were analysed beyond the semantic (surface) to the latent (underlying) level 'to identify or examine the underlying ideas, assumptions, and conceptualisations—and ideologies—that are theorised as shaping or informing the semantic content of the data' (p. 84).

The analytic process involved a progression from description, where the data showed patterns in semantic content and was summarised, to interpretation, where significance of the patterns and their broader meaning were theorised and

the implications of these considered. Therefore, in addition to description, an interpretation of the themes was provided.

#### 2.6.5 Reliability and validity

Taking a critical realist position, I recognised that my position may influence the coding of the data. To help minimise this and increase creditability of the data, SL (supervisor) independently looked at three of the nine transcripts to share observations and interpretations. Myself and my supervisors (SL and MC) further met to review codes and themes across the data as a 'verification step' to review the analysis for discrepancies, corrections and elaborations in accordance with what Elliot, Fischer and Rennie (1999: p. 222) consider good practice.

In addition, Williams and Morrow (2009) propose attending to integrity of the data i.e., clearly articulated procedures (enough to enable replication), researcher biases and a stability check. It is also important for best practice to demonstrate a balance between reflexivity and subjectivity and being transparent in communication. Attempts to address these aspects were made in this report.

#### 2.6.6 Reflexivity

It is acknowledged that this research was constructed and informed by my own experiences (discussed further in the critical review) and the literature. As Williams and Morrow (2009) suggests, 'bias enters the picture as soon as a research question is asked in a particular way, in a particular setting, by a particular person, for a particular reason'. To manage the biases I brought, I adopted the idea of a self reflexive journal and 'bracketing' (Fischer, 2009) to 'shelve' my interests, assumptions, experiences and hunches, which may influence how I viewed the data. The process of bracketing is not to gain objectivity but to make the reader aware of my engagement in the development of the research process. I, therefore, tried to maintain reflexivity and stay attuned to my perspective. Reactions during and after the interviews, during transcription and after supervision and during the analysis were recorded as recommended by Hamberg and Johansson (1999) and discussed in the critical review.



I have identified and described my background, perspective and epistemological position with a view to help readers take my (the researcher's) perspective and to also open new understandings. It has been suggested that when perspectives have been stated clearly, readers can use this information to intentionally take a different perspective and develop alternative readings of the data and this can help understandings progresses. A number of authors stress the importance of being this explicit (Braun and Clarke, 2006; Holloway and Todres, 2003).

### 3. RESULTS

The data from the interviews were analysed using TA and, accordingly, the findings are structured into themes and subthemes based on how the author understood the data. Three themes were devised: 1. The development of a 'risk' lens? 2. Challenges in what is valued by staff and organisations: a need for congruency? and 3. Creating fertile ground for building trusting relationships. These are further detailed in *Table two* below and a visual representation of the data is displayed in appendix J.

TA aims to organise complex data into a framework however, there often some overlaps due to the complexity of data and this is the case here.

*Table two*

Superordinate Themes	Sub themes
The development of a 'risk' lens?	<ul style="list-style-type: none"><li>• Forming initial impressions before meeting a person with dementia</li><li>• How to deal/be with challenging behaviour</li></ul>
Challenges in what is valued by staff and organisations: a need for congruency?	<ul style="list-style-type: none"><li>• A family ethos: 'breaking down of work is work and home is home'</li><li>• Bringing person centred care to the fore</li></ul>
Creating fertile ground for building trusting relationships	<ul style="list-style-type: none"><li>• Building relationships takes time and a commitment to '<i>being with</i>'</li><li>• Utilising personal history in establishing and maintaining trusting relationships</li><li>• The importance of valuing and supporting family</li></ul>

#### 3.1 The development of a 'risk' lens?

##### 3.1.1 Forming initial impressions before meeting a person with dementia

All members of staff spoke about the assessment process by the manager before a resident comes to the home and how information on physical aspects and the person's social history were obtained and put into a care plan. These and

handovers were the main methods for information being communicated about someone coming into a home.

These were always said to be accessible but there were different thoughts as to how much these were accessed, some felt this did not happen enough and two staff spoke of having to direct other staff to these. There was some suggestion that looking at a care plan may happen more when there was a new client or a new member of staff arrived. Most participants felt there was time to read these and that it was each individual member of staff's responsibility to do so.

*'I think I look at them (...)but I feel like some people like that have just started don't look at the care plans and they just rely on other people to give them the information when the actual best information is in the care plan'* (Emma, 666).

*'A lot of carers come in and say what does such body like doing (inaudible) and I can say well go and read their notes and have a look at their activities and what they like to do because it's good for you to learn'* (Lorna, 177).

*'Sometimes is difficult [to find time to read care plan] but if you want to really know something about your client you need to read'* (Dorina, 96).

Most staff initially stated that everything was collected at assessment but about half went on to suggest this was not the case and that they and other staff sometimes knew very little about the person before they came to the home. This could suggest that in depth information was not gathered, not communicated or sought by staff and could influence what information gets heard about a person and what does not.

*'[New staff reported] "To be honest with you sometimes I don't even know erm the residents properly" and I said we need to know them inside out'* (Rachel, 298).

Five participants gave narratives about risk being communicated about clients prior to admission. Challenging behaviours which could include physical or

verbal aggression were referred to in all interviews but for four participants (all from site two) risk predominated in what was communicated about the person between staff. Staff felt they did not know much, other than the risk the person would present and often this was all they were told about a person with no understanding as to why. This could lead to the person only to be seen as challenging.

*‘You really learn and you push it [information] onto the other members of staff (...), it’s not only for his safety it’s your safety as well’ (Daniel, 22).*

*‘All we got told was that he’s really aggressive and that is it like nothing else’ (Emma, 131).*

The focus on risk for four of the participants at site two was considered threatening whereas at the other sites risk was mentioned less and did not seem to be perceived as a problem. Where risk was less of a concern, participants emphasised the importance of knowing and paying attention to likes and dislikes.

It seemed that judgements about clients based on risk information were formed early on, which could lead to seeing the person in relation to their behaviour and diagnosis rather than knowing who they were as a person – their past and current life:

*‘[Staff] get in their own mind what this client is going to be like – are they going to be violent or aggressive?’ (Daniel, 19).*

In contrast, two of the four participants who were concerned about risk stated that knowing information about someone is different to meeting them, suggesting that some staff were able to reserve judgement until meeting someone themselves. There was some uncertainty during the time between hearing about a client and meeting them in person.

*'It's a bit strange because like you are thinking you know what the person's like from their profile but you don't know what they are like because you haven't met them'* (Emma, 102).

Early judgments that a resident was likely to present a high level of risk tended to lead these staff to prepare to observe and detach from the person. It is possible that this could be influenced by prior experience of aggressive behaviour.

Therefore perceptions of risk could influence interactions with clients from admission onwards. There were indications that knowing little information about the person and behaviour may affect staff feeling safe enough to be with the person.

*'We have to (...) mentally prepare ourselves err we can't even be human beings'* (Anu, 135).

*'Some people who don't know much about you tend to not want to like deal with them as much because you don't know what they like'* (Emma, 424).

Where risk was not emphasised initially, most staff seemed better able to think about how the client might feel on arrival and consider the emotional and relational aspects to some extent of coming to a new place and spending time with them. The majority of staff did this to a degree but this varied from orientating the person to their surroundings and carrying out medical checks to there being a more prominent focus on emotional needs which was stated by several members of staff in ensuring the spending of time with the person on their arrival, with a focus on relating. For example in *being with* someone offering emotional support or activity tailored to their likes.

One participant found out a client was sociable on admission and said:

*'Okay we need to set up an activity this afternoon and do a tea party'* (Rachel, 95).

Perspectives and approaches of what to do when faced with risk differed but where risk talk predominated behaviour seemed to be judged as more unpredictable and difficult to understand. This may have been partly because it was difficult for staff to remain curious and be with the person, feeling it was necessary to keep their distance and be on the alert.

### 3.1.2 How to deal/be with challenging behaviour

The majority of staff highlighted the practical and emotional challenges of working with challenging behaviour. For the four staff at site two, behaviour that was unpredictable could lead to negative feelings which could make staff feel threatened, and there was some indication that they did not feel equipped to deal with this.

*'[Challenging behaviour] can be very difficult and very stressful'* (Lorna, 11).

*'I was curious and afraid and scared (...) people they can be violent'* (Dorina, 44).

*'We can't cope with residents who are very verbally and physically aggressive'* (Anu, 136).

When staff were aware of risk, understandings about the meaning of aggressive behaviour and ideas about how best to respond varied. Perspectives and approaches of what to do when faced with risk differed but where risk talk predominated at site two, behaviour seemed to be judged as more unpredictable and less as a communication that the person may be unaware:

*'He lashed out'* (Emma, 143).

*'He likes punching the hell out of people'* (Daniel, 73).

*'She did not know what she was doing'* (Anu, 234).

However, for one participant dementia itself being an explanation for behaviour seemed helpful in accepting behaviour:

*'If they pour a glass of water on you that's no problem. Just put it in your mind she or he doesn't know what they are doing [they have dementia]'* (Patrick, 58).

On the other hand, many participants held beliefs that behaviour could be understood, though some seemed more confident about this than others. Even for some of those who initially expressed that they saw agitated and aggressive behaviour as random, there was still some level of curiosity and a sense that there might be some pattern or trigger to behaviours.

*'It's nearly always linked to something in their past so their pre morbid personality'* (James, 26).

*'I don't know what these people want'* (Dorina, 145).

*'I was thinking if I would have known some more [I might have understood the behaviour]'* (Anu, 532).

There was some suggestion that despite believing behaviour could be understood it was hard to understand a person's behaviour, some participants had made attempts to understand the communication with varying success.

Two participants described cases where the solution tried was medication (although in one case an initial attempt had been made to ask family to find out information with no success). The medication reduced aggression and was considered helpful by these two staff and enabled them to feel they could be spend time with the person. One staff member reported how this in turn led to a better understanding of the person's behaviour:

*'When her medicine got sorted out (...) I found out [through talking to her, she gets aggressive] because she has nothing to do'* (Emma, 537).

This perhaps highlights that staff need to feel safe to spend time with the person and the utility of making them feel so.

There were examples where staff had made sense of challenging behaviours through different means, including being tuned into the person and drawing on history and had found this helpful so they could then adapt the environment or their responses to meet the person's needs:

*'You have to explain to him before even you touch him' (Anu, 344).*

*'I looked through her history (...) she has had the most traumatic life (...) her attitude was to hit it straight on, never give up (...) and that's exactly what she was like in her dementia (...) we just rearranged the house to suit her needs to make sure that if she wanted to do something we would do our best to make sure she did it' (James, 637).*

*'I did (.) [spend time] and there was nothing [challenging behaviour] (mm) I introduced a doll which she absolutely loves (...) because she was actually a nanny before in her time (...) she absolutely thrived she was chatting with the doll and she was stroking it and she was having a real conversation' (Rachel, 182).*

Despite all interviewees stating that the experience of coming into the home must be difficult, this link was only made by about half of the participants as a possible explanation for challenging behaviour:

*'You have got others who are actually very very distressed at having to come in (...) they can show it through all sorts of erm different ways, they can be quite physically aggressive, verbally aggressive' (Kate, 205).*

This may suggest a difficulty for some people to tune into the other persons emotions and perhaps this may be more so when there is a concern of getting hurt and a belief that the behaviour is unpredictable.



For others it was helpful to have a strategy that worked – the path to getting there was less important and they saw this more as a case of trial and error than something needing to be figured out or understood:

*'I suppose the reason why, becomes (...), less important, if we find something that works the reason for why it works is important for learning future stuff (...) but for that person it doesn't matter it works so let's just keep doing that because all the time we are doing that person is content and is happy'* (James, 797).

*'I try and find out myself (...) I got this little knack that I can, if a person becomes very aggressive or really shouts and screams at me I go to his level or her'* (Daniel, 99).

The findings suggested that knowing someone and making sense of the behaviour could help both the resident and the staff members involved in their care to feel emotionally safer but that initially seeing someone through the 'risk lens' may get in the way of this process taking place. There were also indications that there were staff that tried to make sense of behaviours or believed it could be done but found this hard, suggesting that more support to do this may be welcomed and beneficial bearing in mind some of the successes. Where these individuals had not succeeded, this may have led to and confirmed beliefs of unpredictability, making staff feel deskilled and worried, and in some cases maintained the use of medication. Although some found a trial error approach helpful, it may be that not having a theoretical understanding of why a strategy works hinders learning opportunities for staff to develop skills in formulating and confidence.

Making links between behaviours and the context they happened in seemed to be somewhat dependent on having a reflective space initiated by staff themselves or in a supported learning space created by the organisation. This was illustrated by two staff from site three.

*'I thought okay, so maybe she's lonely (...) there's just got to be something and I would go home and think okay, what can I do for her tomorrow'* (Rachel, 215).

*'It is about sharing experiences and sharing knowledge and sharing what works and sharing what doesn't work (...) how to deal with problems that they [staff] face on the floor'* (Kate, 395).

A few participants seemed to start to make sense of clients' behaviours during the course of the research interview, illustrating how space and time to think can allow people to understand behaviours in different ways. For example, when Rachel was initially asked what sense she made of a particular resident's behaviour, at first she responded: *'I really don't [...] I don't know'* (246). However, when asked if they had any ideas, she stated: *'I think with this gentleman people need to respect his wishes'* (248).

In addition one member from site two expressed that there was little opportunity for a reflective space:

*'We don't get much opportunity to sit and analyse what we do very often it's quite it's quite useful it's quite therapeutic (...) [the interview was a] good bit of reflection about how we behave with people and how we how we interact and how we learn from it'* (James, 993).

Only a minority referred to using a reflective space whether at work or in the interview, even though this seemed to enable staff to make sense of behaviours.

Risk was dominant at site two for three care assistants and one nurse which led to judgements, affecting interactions. This focus to risk however was not demonstrated by the manager in terms of how they thought about the client or how they talked about understanding behaviour. However, the manager reflected that incident rates of challenging behaviour were fed back to staff suggesting that attention to risk and reduction of incidents was important at site two. This may have led clients being seen through a 'risk lens'.

### **3. 2 Challenges in what is valued by staff and organisations: a need for congruency?**

#### **3.2.1 A family ethos: *'breaking down of work is work and home is home'***

Working together, clients and staff, *'In a little group'* (Daniel, 198) was valued by staff. The importance of this ethos was highlighted explicitly when one member of staff stated that they believed it was about creating a culture of staff and residents being a family within the residential home:

*'You are a family, erm because otherwise it doesn't work* (Kate, 232).

Two members of staff drew attention to the importance of staff getting on to create a good ethos and most staff made the connection between the reciprocal relationship of staff and clients feeling happy. All staff felt it was important that clients felt at home and the majority made a link sometimes on several occasion of staff and clients being like a family.

Some staff made reference to seeing and communicating with clients' as they would family:

*'I sort of tend to try and communicate with these particular clients in a way that I would with talk to my aunt (...) good morning how was your night? That's the way of making that literal first step [to building a relationship]'* (Daniel, 404).

*'I have one client he can't talk the last days (...) I feel they are my family and I have to go and see him and I say hey and I try to help'* (Dorina, 156).

Sometimes, although the concept of 'family' was not stated explicitly, the value of warmth and intimacy felt by clients and staff from being in relationship was appreciated. Some people talked about noticing and developing warm relationships with clients through getting to know them and this was reciprocal:

*'People have people they gravitate towards, residents equally as much as the carers (...) there will be residents that light up when particular people walk into a room' (James, 548).*

*'She was lovely and she was here for quite a few years actually and er I got very attached to her' (Lorna, 748).*

Being in relationship to clients seemed important but there were indications that feeling close to clients or having favourites was perhaps was not acceptable – suggesting that perhaps some boundaries needed to be kept to. Yet one member of staff pointed out that these feelings were just normal life introducing some normality to relationships. Indeed many referred to relationships being 'normal' like any other.

*'I've got such a soft spot for him – I shouldn't but he's so lovely' (Rachel, 232)*

*'There will be residents that light up when particular people walk into a room and it might just be the lady who works nights on a Saturday you know and they will completely ignore other people because it's human nature isn't it you connect with some people and you can't always explain why you do' (James, 550)*

In the interviews, staff talked about the sharing of personal information and this seemed to vary in degree as to how much personal history staff themselves brought into the relationship. Knowing a resident's history gave the opportunity for staff to bring in their own history and find connections, which could help to stimulate conversation.

*'My dad was in the war [too]' (Daniel, 205) .*

*'When you have that common ground you then are able to start building up a trust and a friendship, you know and just a nice warm environment' (Kate, 265).*

A few participants talked about not only sharing photos and stories from their own family but also inviting residents to participate in their family life – again suggesting a sense of normality as you would in any relationship.

*‘A few of them [came to] my daughters graduation party, I came and picked them up, (...) they had a great time you know and they always used to say oh Lorna I remember when we went to your X’s graduation you know and how’s your granddaughter (...) and they remember that you see they always remember that’* (Lorna, 549).

*‘Whenever we have anything on I always bring my family in (...) if we are expecting residents to talk about their family then we should be as open’* (Kate, 250).

Other staff referred to boundaries in terms of being respectful not to overstep these, taking a more reserved and cautious approach in regards to how you are with someone or what you ask:

*‘He can tell you or she can tell you about herself (...) as little as you can, not overdoing it because [it’s] a private life’* (Patrick, 228).

Most staff made reference to clients liking to talk but a few were referred to as being *‘private’*. Having dementia could make these boundaries unclear and extra caution was perhaps needed:

*‘It’s difficult with dementia because they can’t always give you the permission to breach those rules, they might want us to (...) it’s really a judgement that you make, do you feel that actually we’ve built to a relationship now where actually I can actually call you by a nickname (...), or would you not want me to do that, and it’s a judgement you have to make and if you get it wrong (...) you are going to offend somebody’* (James, 445).

*'If you push that little to much it could go wrong'* (Daniel, 376).

Most staff referred to the sense of family when they were with clients and this seemed to be something staff valued. Staff also appreciated the positive feelings they got from relationships with clients and noticed the links between clients emotions on their own and a few recognised the importance of the effect of team emotions as a whole on the client highlighting the importance of people working well together as a family. Although family and warmth were talked about and many worked on breaking down boundaries others were more aware of them and more cautious as to what was okay.

### 3.2.2 Bring person centred care to the fore

Participants indicated that for some staff, doing tasks and getting jobs done was seen as important, more so than *being with* residents:

*'If they need our attention we will tell them can you please wait'* (Anu, 258).

*'They often say well I got this to do'* (James, 153).

Several staff made reference to other staff being 'task orientated' and felt concerned by this and one suggested that staff felt they were 'skiving' and felt 'guilty' for sitting with clients (James, 1026).

In the interviews many staff gave examples of spending time with clients but it was highlighted implicitly and explicitly on a few occasions that sometimes staff would *observe* residents rather than *being with* them. One person highlighted that staff may be better to utilise this time to talk to the residents:

*'Instead of just sitting like watching everyone you can go and talk to one of the residents'* (Emma, 584).

For others being present with the person attending to psychological well being was considered more important.

*'If you are with a resident is more important than doing laundry so spending time with the resident and making them feel happy (...) not just sitting there lonely'* (Emma, 396).

*'What's more valuable to someone with dementia is sitting down and holding their hand and giving them time and reading the paper [which they may find difficult to read]'* (James, 145-150).

*'Even if they are on the toilet you have to respect their dignity (...) because sometimes (...) you think oh my goodness [the time], no you are with somebody you are with an individual and that's all that matters that person for the moment'* (Rachel, 279).

Most staff spoke of using tasks as an opportunity to talk with the person with the aim of trying to achieve both 'doing' and 'being with' the person. Many staff interviewed felt that staff could also make time to be with clients outside of personal care tasks and that it was each staff member's personal responsibility to do so, to make it happen and therefore needed to be valued by the staff member. Many said you could find even a short time to find out about family, or to ask how they were.

*'Well it's (.), I think it's down to the individual myself [to make time]'* (Daniel, 176).

*'It is about grabbing a moment and maybe just sitting with somebody and thinking I have probably got five or ten minutes'* (Kate, 501).

The concept of 'protected time' was introduced at site two to encourage staff to sit down and talk to residents – by turning this into a required task it was hoped this would make it happen – though some sense of disappointment was felt that social interactions may only occur if encouraged in this way:

*'They needed that label to put on it to justify to do it it sounds bonkers'* (James, 1028).

The manager felt there was *'a better atmosphere around the building because on the whole residents are happier they have closer relationships with the carers and therefore there's less conflict and less upset (...) but also the carers have a better understanding of the clients and the care delivery is better'* (James, 176).

Although staff spoke of valuing *being with* the person there was reference to this needing to be negotiated where there were tasks (for example, when the staff member was in the middle of arranging medications, but still tried to give a window of time) or where people became aware of risk, and occurrences on the floor which can be unpredictable.

Participants' views were mixed in terms of whether or not *being with* a person was valued more or less than doing tasks in respect to their practice and their colleagues. The staff at site two seemed to mention this variability more.

Two participants referred to the importance of having a happy team as this had an effect on residents' wellbeing. One felt that staff holding different values could lead to difficulties in communication, which could then have a detrimental effect on the care they gave and therefore the wellbeing of residents.

*'Because there's some people you get along with and some carers you don't (...) so there's really bad communication (...) and then that causes an argument (...) and that effects them [clients] because they are seeing that you are arguing'* (Emma, 459).

Several staff talked about common misconceptions held about people with dementia in terms of their abilities *'people think they are dead'* (Dorina, 332). One person felt that people with dementia were treated like outcasts and that people were not interested in trying to understand until their relative had dementia,



suggesting that people with dementia are still not permitted personhood. Some staff talked about the importance of recognising the person as a person:

*'They still got their self well being you know, so you can talk to them'* (Lorna, 103).

A few participants, all at a senior management level, reflected on the history of care. One participant described having worked in a task-orientated setting in the past and that they were in the 'minority' (Kate, 126) wanting to be person centred. This participant advocated training an approach based on feelings – putting oneself in the person's position helped move away from task-orientated work, expressing:

*'[It] presents such a lot of well being, because what you then find is, is that person builds up a trust'* (Kate, 316).

There was some evidence of moves to try and get away from a task-orientated approach and meet emotional needs for example using a memoir box:

*'It can be anything it can be like a box (...) erm sort of with all the information in there erm like this gentleman was a roof tiler erm even bit of tiles can go in there may be they can have a chat (...) he can have a feel erm its just little things (...) anything erm as long as it's about them'* (Rachel, 306).

### **3.3 Creating fertile ground for building trusting relationships**

#### **3.3.1 Building relationships takes time and a commitment to 'being with'**

'Being with' was seen as most important when family were not around, with an emphasis on really needing to tune into the here and now and peoples' emotions:

*'You are trying to make connections through the work you are doing'* (James, 500).

All staff members made reference to the fact that the person with dementia may feel insecure initially coming to the home. Some staff reflected on the person's circumstances, where it may not have been their choice. Staff referred to what a strange and confusing place it must be for them and many frequently made reference to the importance of helping clients feel safe.

*'Going into a nursing home (...) really isn't a choice by them'* (James, 44).

*'You must be at least like what's going on where is my wife or where is my husband or where is my family, you will be asking yourself why am I here'* (Patrick, 27)

All staff used themselves and their own emotions at some points in the interview like compasses to guide how they were with clients and to imagine how the person may be feeling and this approach had the potential to contain clients.

*'I can quite understand - I have two children of my own, someone is preventing me (...), come hell or high water I am getting out of this place'* (Kate, 224-227).

Recognising this need for safety and comfort seemed an important part to connecting and building relationships.

Several staff talked about the importance of *being with* clients in the moment and joining people where they were at, this being reminiscent of the approach of mindfulness. For instance, one person gave an example where a client did not have any verbal communication but they were able to build a relationship with this person by spending time with him eating his lunch:

*'Just me and him sitting down maintaining eye contact at eye level everyday and spent that time with him (...) [without a] time constraint to it'. Non-verbal signals from the resident confirmed his participation in the relationship 'He will maintain eye contact (...) move in such a way, (...) that I believe he is either trying to shake*

*my hand or engage with me'* (James, 297), suggesting that *being with* someone could help build trust.

Several participants gave examples of responding in the moment to non-verbal communication seeking affection such as responding to the reaching of a hand or taking someone's hand and sitting with someone - giving the opportunity for interaction and reciprocating hugs.

*'We have one particular resident who is very very needy in the fact that she likes to have lots and lots of cuddles and that suits me down to the ground because I like lots and lots of cuddles too'* (Kate, 552).

To build relationships maintaining regular contact for example 'it's a touch on the arm or...' (James, 519) were considered important.

Providing opportunities to be with the person enabled new information to be discovered. Staff talked about how spending time with clients led them to discover what made them unhappy and what might alleviate this:

*'Like this man he was business man he doesn't have family I think its very hard for him when he saw relatives come for another resident to be like family, yeah, so (.....) for this person who was alone, it's not very nice and I know he is hurting (...) he try he told me, we try to talk, come I want to show you something (...) if you try to make easy for him'* (Dorina, 217).

*'If she's having a bad day we would say Laura is having a really bad day erm shall we start setting up the balloon game and that changes Laura's complete mood she starts giggling'* (Rachel, 105).

This suggests that opportunities to 'be with' could offer an opportunity to learn what helps to meet a person's needs. Without this time to 'be with' staff felt they would not discover information that utilise later could help them care for the

person. This information could be valuable to help care in the present and the future:

*'They will not tell when we are busy time you know, they will not be able to express anything because they think that we are busy' (Anu, 294).*

By spending time with them, communication could be better understood by staff, which contributed to *'friendship[s]'* (Daniel, 189). Spending time therefore helped to better respond to the person.

However there were examples where difficulties in communication had the potential to get in the way of *'being with'*. Communicating was considered difficult with some clients who had less verbal communication or whose verbal communication was less clear. Staff felt it was important to try and communicate and gave examples of also trying to use non verbal communication but showed some reservation as to whether this was effective or not. Quite a number of staff indicated that clients could not communicate but later said things that contradicted this view. This perhaps further highlights that non verbal communication was difficult and not so familiar.

*'All you can do is talk to them but now she's in a stage now where she doesn't communicate anymore' (Lorna, 335),*

*'You might see they have a miserable face and you say something to them and they laugh they can't talk but they laugh, they know what you're saying' (Lorna, 718),*

*'Like today I said to one of our clients oh you know there's a hurricane heading towards America Florida you know and they they nod their head yeah I said you know its Florida you know they're evacuating, then you get a smile yeah yeah so, whether they really understand or not but (.) you know (but you get a response) yeah you still get a response' (Lorna, 729).*

Despite best intentions, there is a fine line between looking out for non verbal communication and potentially inadvertently acting as though the person is unaware:

*'You don't hear what they say because that's how they are, but all you need to do is put a smile on your face and say oh yeah yeah' (Patrick, 332).*

This highlighted the challenges of communicating with clients and could get in the way of the person being heard. Other staff suggested that some colleagues were less good at trying to communicate, whether this was because communication was not valued or was perhaps too difficult:

*'Not many people communicate unless they have to' (Emma, 578).*

*'You got to learn how to listen, be patient with them, don't go oh and walk away [staff member conveying that he had to say this to other staff]' (Daniel, 187).*

*'In the past, a lot of residents I have come across, once they get to that stage where their communication is very very limited they tend to be ignored because people then don't know how to interact with them' (Kate, 348).*

Staff often noticed clients responded using non-verbal communication and several gave examples of noticing and appreciating this. Some participants gave examples where they were able to adapt their communication using non-verbal methods, although they were not always sure if they got their message across and whether the client understood. Staff indicated that taking time to be with residents enabled them to better understand the person:

*'Even if they can't talk [they know what is going on around them] (...) you can follow their eyes' (Dorina, 186).*

*'When you get to know the person it's better to communicate with them (...) after a while you (...) get a better understanding (Emma, 285).*

*'Being with'* enabled opportunities to hear and support preferences. There were a number of examples given in interviews where clients had expressed preferences. In some cases these had been supported by staff for example one gentleman said he would like to talk with staff more and the staff member told this to her manager *'To make sure someone every half an hour [talk to hi] which will make him happy you know'* (Anu, 285).

There were examples where clients had expressed their gratitude:

*'Oh he was really appreciative "oh great thanks a lot you're my star your my saviour"'* (Lorna, 309).

This had the potential to contribute to building trusting relationships. However, a few participants referred to occasions where clients' preferences were not prioritised. In one case this was explained as being due to concerns about health risks and in another case the favouring of staff's preference had resulted in distress.

The process of *'being with'* enabled new discoveries which could have an effect on seeing the person as a person being able to talk *'When they talk they live'* (Dorina, 331).

*'She said to me 'you know I always used to like painting men in the nude' I said really urgh that's disgusting yeah men in the nude 'oh they had some lovely bodies' you know what I mean stuff like that and erm you know I just found her amazing she's a really great lady'* (Lorna, 791).

The opportunity of seeing and responding to the person to build relationships happened from *'being with'*.

### 3.3.2 Utilising personal history in establishing and maintaining trusting relationships

Staff spoke of knowing something about someone as key to making an initial connection giving them an *'in'* (James, 831) on conversation. It was considered helpful to guide staff in how to be with the person, for example what to talk about or how to be in their demeanour. It enabled clients to be matched with staff with shared interests and personalities. In addition most staff expressed that having access to memorabilia was helpful in connecting with people, photographs were often mentioned as a way of connecting: *'Who's that up there? [referring to photograph]'* (Daniel, 208).

Staff spoke of the importance of knowing peoples interests, hobbies and occupation which enabled them to talk to the person on a daily basis and support them in continuing activities that could invoke positive feelings.

*'You can communicate with them on a daily basis about um about their previous occupation, what they used to do'* (Lorna, 78).

Some staff spoke of knowing what music the person liked as helpful and the pleasure it could bring:

*'I know he like a one song er my bonnie to me [staff sings] and all the time I and I put this song on special for him and he stand up and I stand up with him (...) I feel I did so much for him cause I start to sing and my colleagues they start to sing for him and its really something big, it's nothing may be for normal people but for them'* (Dorina, 195).

*'A simple thing – but its big, you've got this little bit of information (...) that may be a tiny bit but it's made a very very big impact on that person'* (Kate, 644-645).

It was felt by the majority of staff that the more information that was known about a person, in terms of their likes and dislikes for example, the better the care that

could be given. Without *'knowing'* staff felt care would become like a *'mechanic'* (Anu, 474) and *'task orientated'* (James, 336) following staff and organisational preferences rather than the persons.

Most staff said that knowing a person's history and particularly their everyday preferences showed respect and helped provide a sense of safety making the person feel more at home following their routine rather than the homes:

*'He's happy because he's following the routine he's done [going to church]'* (Anu, 61).

Avoiding dislikes was also seen as important to prevent upsetting circumstances – for example knowing peoples difficult experiences *'[so] you don't kind of bring those issues up'* to prevent 'upset' (Patrick, 250).

Staff spoke of the utility of knowing a person's past so that they could trigger those memories for them in conversation to evoke *'a nice memory'* (Kate, 48). In some cases this was used to help generate positive feelings when people were down. Either way holding onto and utilising stories helped to form and maintain relationships and help clients' feel safe:

*'When anyone comes in [the client says] leave me and my friend we are talking'* (Patrick, 79)

*'I think probably it's [their memories] that one place where they felt safe, they were complete'* (Kate, 56).

Reminiscing and therefore utilising the past could rekindle happy feelings and a feeling of importance for the person, when others became aware of what they achieved. This enabled staff to appreciate the person and to consider them in the context of their life:



*'He was a milkman he was always talking about that (...) we used the internet and we'd do street view Google and he was actually able even through his dementia (...) [to] walk his milk round (...) he burst into tears (...) through happiness (...) and that was lovely which then set me off and everybody else in the room, it was a beautiful thing (...), he had a genuine joy from that'* (James, 213).

*'When person give you the history of himself or herself [you think] (...) they were once like you or more than you'* (Patrick, 140).

One person said knowing history enabled opportunity to let people know they are valued by asking their opinion on something they would know about:

*'It's like anything isn't it if I asked for your opinion that means I value what you have got to say, it means that I am asking you because I trust your opinion'* (Kate, 284-286).

In addition the act of just staff listening to a person's story enabled an opportunity to feel valued – making them feel important.

### 3.3.3 The importance of valuing and supporting family

All staff stated that clients' family were an important source of information: *'Family is definitely the key feature'* (Kate, 468) in getting to know the person. This was seen as particularly important where the person with dementia had difficulties in verbal communication. Not only were family able to offer good narratives of a person's past history they had access to personal memorabilia which could help staff to build relationships.

About half of staff reported good relationships with families and most of these staff made reference to asking relatives information about the client in trying to provide care suggesting that relatives were the experts. However, there were a few staff who were less active in information seeking or responding to relatives asking for information.

When asking Daniel if there was an opportunity to ask the family for more information he responded:

*‘ Well (.) no not really, we don’t, we don’t sort of, well I don’t (.) I don’t sort of carry (.) I try and find out myself [what helps]’ (Daniel, 98).*

Indeed it was the staff in the managerial roles and a senior member of staff who had worked in the field for a long time who made reference to seeking out contact with relatives often to try and get a better understanding of the person’s history. This may have indicated a difference in the perceived utility of this or confidence in staff’s positions.

Family did not just come with potential knowledge of information but also with a need for emotional support, and this was recognised by several staff. Offering emotional support was considered important in building relationships with them and the client. Staff talked about how putting their relative in a home often led to family members experiencing difficult feelings and one person raised that families may be scared for their relatives to move into a home due to the bad press in society. This participant made reference to a man showing concern of his wife’s bruises: *‘I know what goes on in nursing homes’* (Lorna, 441).

*‘There’s a huge amount of guilt and repercussions for the family’* (James, 44)

*‘You hear some nasty things about homes’* (Lorna, 115).

Staff spoke of the difficulties families had being around their relative and people with dementia, and the difficulty of adjusting to a change in their relationship with their relative.

*Their relatives might get up and say “I’m going - I need to go” because they find it very difficult to handle’* (Lorna, 428)

*'They have found it very very difficult to accept (...) they have become a completely different person' (Kate 26).*

*'It's (.) heartbreaking for her daughter (...) she just sits there and there's no verbal at all' (Rachel, 361).*

A few staff were aware of relatives' struggles and tried to support their emotional needs, offering education and strategies to help relatives to spend time with the person and connect. Examples of this were reassurance that the person does benefit from family presence and the use of meaningful objects.

*'Relatives say to us I don't know why I bothered coming' and 'They [client] may not remember that person coming but there is an intrinsic value that is passed on through that human contact' (James, 231)*

*'[Bring in personal items] You can make a connection with them' (Kate, 39).*

Several staff suggested that asking about the person, and showing an interest in the client could help relatives manage their anxieties. For example one person reflected that offering emotional support to relatives could help support the person with the dementia, since having relatives around was felt to improve their wellbeing:

*'If they [relative] are happier the visits are more successful and their interactions with their loved ones and so forth, and so it goes round in a full circle and then the residents are happier which makes the relative happier' (James, 231).*

Although all staff felt getting history from the family was important, only half of the staff talked about families needing emotional support, and even fewer suggested that by staff having good relationships with relatives perhaps offering a source of containment, that this would help the person with dementia feel happier as the family could feel more comfortable being in the presence of their relative. It was predominantly those staff from site two whose voices were heard in theme one

surrounding risk that did not comment on the emotional needs on family and may suggest tuning into emotions is more difficult when fear and a *doing* approach is more prominent.

## **4. DISCUSSION**

This research set out to gain a better understanding of care home staff's perspectives about getting to know individuals with dementia. The research questions were i) what are staff's experiences of getting to know individuals with dementia? and ii) what helps/hinders opportunities to get to know an individual in a residential care setting? The results will be discussed in relation to the existing literature below.

### **4.1 Discussion of findings in relation to the literature and research questions**

#### **4.1.1 The development of a 'risk' lens?**

Although this research did not set out to make comparisons between homes some patterns were observed which is perhaps not surprising given the intensive training received by site three, as will be further discussed. It was evident that risk was much more prominent in the minds of some participants than others and the issue of a risk lens developing was predominantly based on the interviews at site two. This theme was felt significant in that it postulates on the possible development of a risk lens at admission to a care home and also provides information from other interviewees of other aspects or approaches that may be focused on.

This theme highlighted some of the processes that take place prior to admission, including what information is communicated to care staff and how an emphasis on risk can get in the way of feeling safe to spend time with clients. Indeed, physical aggression has been considered to be the most challenging behaviour that staff encounter in care homes (Fisher, Fink and Loomis, 1993), with cognitive impairment and behavioural problems contributing to admission to a care home (Bannister, Ballard, Lana, Fairbairn and Wilcock, 1998; O'Donnell et al., 1992).

Risk of aggression was a predominant focus for most of the participants at site two in terms of what was communicated about the person and the use of distancing to manage this. For the manager at site two, although their description

of the admission process did not suggest an emphasis on risk, there was evidence that they prioritised communication of risk when meeting with staff. This suggested there was an organisational value around attending to risk.

There are a number of aspects to consider here, firstly, in thinking about what and how information is communicated to staff, why risk awareness is so valued and the implication of this on the person with dementia in terms of their identity and the opportunity to build relationships with staff. Certainly, in Western society there has been substantial attention to minimising risk (Giddens, 1990). Adams (2001) suggests that in mental health nursing, risk is associated with thoughts of hazard, threat and loss. There has been a wealth of literature about risk aversion in health settings and this is greatly valued, for example, by commissioners and inspectors. Despite policy and inspectors conveying the importance of psychological wellbeing and the monitoring of social interactions now conducted in inspections, institutions and organisations are more likely to be scrutinised if incident levels are high, having implications for business (Sheard, 2011).

Therefore, it may be that these discourses lead to risk being prioritised, even though psychological wellbeing may be valued by management. Warner et al. (2010) support this, suggesting that the quality of life in care homes is influenced by internal issues and external factors, such as regulation and competition. Alaszewski and Manthorpe (2003) suggest this has the potential to constrain and obscure opportunity. There is a question about how managers contend with this pressure and fear around risk so that it does not permeate the system. Managers' concerns could have in this case been passed on to the staff, with negative implications for their clients. This study indicated that staff detach themselves from clients, thereby reducing opportunities for relationships, which are so essential for wellbeing, as well as our sense of identity. In addition, there are implications for staff's emotions.

The uncertainty around risk, coupled with the feeling that residents' behaviour was unpredictable had an emotional impact on participants in site two, causing some stress. For some staff, having been hurt was a reality, and how staff are

supported to cope with this, and possible future events, is likely to have an impact on how well equipped staff feel emotionally. Brown and Calnan (2012) discuss different ways in which staff may cope with uncertainty and vulnerability, proposing that often this can result in a more bureaucratic strategy of control from management, which may reinforce people's concerns. However, Brown and Calnan also suggest that others take a relational approach focused on trust and this can be beneficial. This perhaps describes a distinction between site two and three.

For staff to build trust with clients and provide emotional containment, they need to feel emotionally supported, understood and contained themselves (Bion, 1989; Menzies-Lyth, 1988). If individuals do not feel safe this may lead to the detachment described. There have been suggestions (Kitwood, 1997) that risk may be a defence against staff's anxieties and this can lead to a focus on task-orientated work and, therefore get in the way of building trusting relationships. This in turn has implications for quality of life for the person with dementia and staff.

In the interviews, staff varied in their beliefs around the meaning of behaviour of people with dementia. In some cases clients were seen as not knowing what they were doing, suggesting they were not aware, and there was some indication that this was just seen as a normal part of dementia, supporting Dupuis, Wiersma and Loisel's (2012) findings. Interestingly, this belief varied within, as well as between, participants, perhaps suggesting some uncertainty about how to make sense of the behaviour. Many participants understood behaviour as a communication but there was often little attempt to work out what this communication was and when this was attempted, it was not always successful. This meant behaviour was often not contextualised and in most cases history was not considered as a contributing factor to behaviour, despite a wide body of research suggesting this is important (Kitwood, 1997; Stokes, 2000). This has implications for clients in not being understood and consequently their needs not being met, thereby threatening personhood, since how the person views themselves depends partly on responses from others (Gergen, 1971). Where

history was discovered by staff, this helped them and other staff make sense of behaviour and understand it in the context of a person's biography and/or provide emotional support. Research suggests that psychological interventions can offer a better alternative to medication (Ballard et al., 2001, Fossey et al., 2006).

In one case, there was a rather different approach when the participant was told people had challenging behaviour on admission. This staff member spent time with a person and got to know them, focusing on building relationships. Although not the main intention, it seems likely that such an approach would reduce aggression and other behaviours communicating fear, anger and other negative emotions experienced by the person with dementia. This therefore seems in line with what Sells and Shirley (2010) describe as a person-centred risk management approach; this attempts to address risk by staying focused on the person. Utilising the concept of traffic lights there are three stages. The first, drawing on ideas from Kitwood (1997) and Stokes (2000), encourages staff to prevent risk by meeting ongoing need by basing care planning on personality, likes and dislikes, communication/cognition, activities/occupation and environment. Interventions are planned based on these. For stage two, staff consider how to respond to behaviour that challenges and stage three involves devising strategies to be used in an emergency situation. The approach stresses the importance of knowing about a person's: physical health, personality, mental health, life story, social environment, neurological impairments and medication. This is in line with the Newcastle model (James, 1999).

It is possible that if staff hold a belief that behaviour can be understood and have some experience where understanding behaviour leads to a solution, this may help them feel more in control. Conversely, not holding this belief (i.e. that behaviour is unpredictable or not having experienced that understanding behaviour can lead to solutions) seems likely to lead to further uncertainty and lack of confidence. In the latter situation, medication may be used, implicitly suggesting the problem is in the person and conveying a message that staff cannot cope. As discussed in the introduction, there is a drive to reduce this approach (NICE-SCIE, 2006). Therefore to understand behaviour in context



seems beneficial to both client and staff and understanding how we can do more of this seems key.

Although only illustrated by three participants, having a space for reflection in this study seemed to be helpful to begin to make sense of a person's behaviour. At site three one participant said that making space to discuss difficulties on the floor was helpful for staff, and although it was not known how often this regular learning space occurred, this could offer containment as well as learning from others. In addition, the regular practice of engaging in this may enable these skills to develop outside of this space, i.e. on a daily basis, to take time to personally reflect or discuss dilemmas with colleagues. This was valued in Palmer and Withee's (1996) research with care staff. Such a learning space for staff where peers offer support can, Cantwell (1992) suggests, enable a creative learning environment. This highlights the importance of staff needing to feel safe to be in a position to learn. Indeed, Kitwood (1997) proposed person centred care for the carer, questioning how clients can flourish if staff themselves are not supported to do so, therefore, emphasising the importance of thinking about and being interested in staff as persons.

A forum to discuss challenges such as behaviour may enable staff to feel more skilled, whilst with little feedback staff may well feel incompetent and deskilled. Jones (2008) has also discussed the importance and effectiveness of reflective spaces for staff. This supports Kitwood's (1997) belief that staff need to feel contained to contain the client and that often there is a lot of anxiety for staff, yet there is no space to address this in many settings. However, Ward et al. (2006) suggest that little time tends to be available in organisations for this 'invisible workload to be managed. The consequence of this is that anxiety can be re-channelled into a defensive system which can lead to paralysis, a resistance to change and a barrier to emotional engagement and to splitting, for example between staff and clients (Klein, 1935 cited in Jones, 2008).

Palmer and Withee (1996) conducted research using an educational training programme to help staff implement psychological interventions to address

aggressive behaviour. They suggested that when staff have a space where their feelings are first acknowledged in relation to the behaviour, this can help to contain anxiety, increase confidence in managing difficult behaviours; this then results in feeling less at risk and with a greater sense of personal safety. In addition, incidents decreased, which may be a result of staff confidence and/or be a result of more effective interventions. Sells and Shirley (2008) also reported that staff did not seem to feel confident in managing risk and needed to feel safe and in control.

Janes and Shirley (2008) have recognised the use of creating a reflective space when utilising the Newcastle model (James and Stephenson, 2007) in care homes to help understand behaviour that challenges. Meeting with staff, family and friends using this model to formulate behaviour that challenges enables not only a space to share ideas and reflect but in doing it enables a process of re-personalisation (Janes and Shirley, 2008). This then enables strategies to be derived to meet the persons needs forming the basis of care plans. Staff have suggested the Newcastle model has have been helpful and that carer distress previously experienced can reduce as a consequence (Wood-Mitchell, Mackenzie, Stephenson and James, 2007). The approach has also helped see the person created warmer feelings by staff, prior to this staff spoke of being reluctant to be in close proximity but now felt comfortable to sit and be with the person. Janes and Shirley (2008) suggested that the process of actively involving staff is important in compliance and found that staff liked the 'detective work' in formulation. Indeed, clients in the current study showed some curiosity in trying to make sense of behaviour but also some hesitancy as to how to go about it; formulation did not seem to be a well-known phenomenon and the space to do this was not readily available. It may be that understanding the rationale behind why a response they give to clients is helpful could contribute to staff's sense of safety as they develop skills in formulation.

In summary, a reflective space serves to contain staff anxiety and help staff develop skills in making sense of behaviour, in turn improving their confidence to manage difficult situations. Although introducing such interventions has been

noted to be time consuming it has also been considered worthwhile and effective (Palmer and Withee, 1996).

Before drawing conclusions, it is important to highlight that site three had received input from Dementia Care Matters (DCM) and, therefore, had received a lot of input around feeling-based care, which is what DCM advocates (see methodological limitations for further discussion). Although it is not possible to draw conclusions about causation from this qualitative study, it seems possible that taking this stance may give staff permission to focus on the person and, thereby, provide staff with a different approach to their work. As highlighted in these interviews, they were able to think how the person may feel when admitted to the home and the two unit managers emphasised the need to attend to emotional and relational needs when someone came in, for example setting up the environment and offering emotional support. The manager at site two also alluded to this but although mentioned by other staff at this site this was with less emphasis and detail

It is important to consider further the contexts that different participants were working in. At site one and two it seemed that residents varied in their stage of dementia, whereas at least two of the staff at site three worked more with clients who were in the earlier stages of dementia and, therefore, may have been better able to communicate their needs in a way that was less challenging.

Overall, this theme suggests that containing staff by developing reflective learning spaces to talk about how they feel and to be supported in understanding a person's behaviour would be beneficial in the wellbeing of staff and clients, to help staff connect with clients earlier, for clients needs to be met – to be treated and respected as a person. However, to really tackle the issue it is important to consider the organisations values, for these to be reflected on and to address the discourses in society. Despite documents such as '*Living well with Dementia*' (DoH, 2009a) and research highlighting the importance of attending to the person, risk seems to continue to overshadow care practice, eliciting fear. It is

important to consider how risk can be kept in mind whilst the values of person centred care are also incorporated.

Risk was less talked about at other sites and it may be hypothesised that site three's ethos, and training on focusing on feelings of the person and relational aspects, may have helped detract from risk as a main focus; with staff able to think more about what clients may be feeling on admission.

#### 4.1.2 Challenges in what is valued by staff and organisations: a need for congruency?

There were incongruencies in what was valued by staff in their work. The concept of being an extension of residents' family seemed valued by staff, perhaps as a way of trying to ensure respect towards them, and in some cases reduce the power differential of 'them and us'. However, there seemed to be a continuum where at one end staff spoke of approaching clients as family, breaking down boundaries by exchanging personal information and involving their own family, whereas at the other end were staff who were more cautious and mindful of stricter boundaries, some emphasising these were necessary. In the middle were those who felt cautious about where the line was and whether it was okay, for example, to have warm feelings for clients or call a client by a nickname. Clients having cognitive impairment perhaps made these boundaries more complex to negotiate because the person was seen as less able to consent. The results suggest some breaking down of the 'them and us' culture that has dominated dementia care for so long. However, Sheard (2008b) draws attention to the difference between 'doing' person-centred care and 'being' person-centred. It seemed that where some people held the idea of family, a few were actually taking this further in *being* like family.

The notion of 'boundaries' has a historical context in psychology and psychotherapy, and as such is often emphasised as part of training in health and social care settings. On the other hand, a sense of 'them and us' has its own legacy in the institutionalised practice of care. These and other longstanding

discourses around relationships between people with mental health difficulties and those involved in their care are likely to have some impact on organisations' and individual staff's views of what feels comfortable and appropriate, in how close to be with someone and how much to share. As stated above, a number of people have suggested that staff keep some separation from those they care for as a way of defending against the difficult feelings that tuning into clients' distress and other lived experiences may evoke (Menzies-Lyth, 1988; Sheard 2010).

This apparent similarity between different participants' narratives about being residents' family, but potential qualitative difference in how different participants acted on this, may make a difference to relationships with the person. Both suggest a degree of empathy, a good intention to act in a certain way but the integrating of one's personal life with that of another may or may not make a difference. In thinking about personhood and how we are with people with dementia integrating our personal and professional lives may help promote this, as reciprocity does in most relationships in everyday life. It seemed that some staff felt more comfortable, freer to do this than others, who remained more reserved. Sheard (2010) discusses the notion of professional detachment and how attachment is more helpful in attending to the needs of the person as well as being more integrated as a whole in professional and personal life. There was evidence that sharing invited opportunities and warmth to these relationships and, therefore, that breaking down these barriers was helpful. How to break these barriers down, however, needs careful reflection. Kitwood (1997) and Sheard (2010) suggest it is the breaking down of defences and attending to emotional level that is needed, with staff being cared for first to then be able to attend to others' emotions.

Alongside the tension of how close to be with someone was the tension of what was valued, between *being with* clients and attending to tasks. This is perhaps not surprising bearing in mind the continuing literature and references made to the history and continuation of task-orientated care, which has long prevailed. Attempts to truly achieve person centred care have been much harder than proposed. It has been suggested that person-centred care has become

institutionalised, and it is less often a reality than suggested by the glossy covers of care home prospectuses. This is in fact, what Kitwood (1997) feared.

Sheard (2004, 2010) proposes that to achieve person centred care, the concept has to be felt by care staff before it can be provided, drawing attention to person-centred emotion-based care for staff, emotional awareness and reflective practice. Training, he proposes, needs to help staff develop 'emotional intelligence', whereas most dementia care training to that point had been focusing on how to give practical care.

The current research highlighted the tensions between managing tasks and spending time with people, as discussed by Ward et al. (2005) and suggested that different participants valued and prioritised these to different degrees. In a few cases there was a sense that *being with* someone was not seen as work. Historically, psychological work has not been valued in dementia care, and yet Ward et al. (2006) highlights that there is an 'invisible work load' of emotions that need attending to, of both staff and clients. As a society Sheard (2010) proposes that we are less good at addressing emotions and therefore it is perhaps not surprising that it is sidelined. Indeed, what is valued in society is likely to take priority – in Western society cognition and productivity are highly valued (Post, 2000). These ideas, as well as those outlined above related to keeping a distance from clients as a defence system are obstacles to shifting from doing to being. Commissioners also reinforce this pattern by prioritising outcomes that are achieved by 'doing' rather than 'being'. Sheard (2011) suggests an organisation can receive three stars by just achieving minimum standards and legislative requirements – quality of life still not being a priority and that feelings matter most is not key to commissioning.

For participants to spend time *being with* residents, it seemed this needed to be valued by staff as individuals, but this could be potentially threatened if not supported by other colleagues. Indeed, congruence between team members seemed important. With some being emotionally in touch and others less so, tensions in the team and inconsistent practices limited the opportunity to get to

know a person. To manage these tensions, protected time had been introduced in one home, highlighting an attempt at a shift in culture. Another idea was to use memory boxes to provide a tangible way of *being with* someone. Spending time with people and getting to know residents was higher on the agenda of the management staff interviewed, but this did not always seem to have filtered down to care staff interviewed, suggesting that consideration is needed as to how prioritising '*being with*' is communicated and implemented. The rationale needs to be understood and most importantly the process felt to be beneficial by staff (see recommendations regarding training).

Sheard (2009) suggests four types of conceptual organisations: firstly- the Clinical Service, a traditional old culture organisation, which he describes as an emotionless organisation, promoting clinical services with a powerful and controlling defence mechanism limiting the emotional impact of the service. Secondly- the Confused Service, which has no effective defence mechanism of limiting the emotional impact throughout the service. This service exposes staff to new beliefs in person-centred care without effective means of implementation as the service is still task-based and run on an old culture of professionalism, leading to elements of staff stress, disillusionment, ill being and burnout. The third is a Creative Service, which has many new culture beliefs and approaches in place but these are mixed in with old culture actions. The service is likely to have no clarity that lack of effective training and lack of application of person-centred approaches to staff teams is defeating its intended purpose. This leaves staff exposed, with no defence mechanism to handle the lack of congruence in the service between the service's intentions and its muddled daily approach. The fourth is the Congruent Service, a new emotion-led organisation providing congruent services, with its beliefs, training and action compatible to people living and working together. This is effective in promoting and valuing emotions at work and supports this way of working by formal and informal means on a regular basis.

It seemed that at site two and three different models may be operating, with less congruence at site two and greater congruence – being emotionally led – at site

three. In fact site three was supported by the organisation which Sheard directs. Kitwood (1997) suggested that getting organisations to change can be hard and that defences need to drop to get to this emotional level – to be with people.

These tensions suggest the concept of person-centred care, if not lost by being institutionalised, is still in a state of instability, with task-orientation still at the forefront in some care systems. Tackling what is valued at a wider level in society seems essential, with more action. Policy papers are a start but not enough for real change.

#### 4.1.3 Creating fertile ground for building trusting relationships

This theme illustrates what staff found helpful in their work on an individual level to build relationships with clients when getting to know someone. Being present with clients in the moment, joining with them and tuning into where clients were at emotionally, and in communication (through verbal and non verbal means) were helpful in better knowing how to be with the person and learning about the person. Being present and attending to a person's feelings – having empathy – has been increasingly emphasised and is central to the training provided at site three on feeling based care (Sheard, 2004, 2009). Taking the time to be with someone is seen as crucial to the notion of personhood - that we are persons when in relationship with others (Kitwood, 1997).

Good communication has been considered as essential to help clients maintain identity (Hubbard et al., 2003). Staff were able to use themselves to try and understand how things might be for the person which may be considered particularly important where clients find modes of non-verbal and verbal communication difficult. Spending time with a person could help create opportunities in understanding the person's communication which could at first appear unclear but with time could be understood and was likely to have implications for their future relationship. Research suggests that those individuals with more severe dementia and with difficulty communicating are those who are most likely to be isolated (Hubbard et al., 2003). Yet there were times where staff picked up on non-verbal cues and sometimes seemed



surprised at this. These examples lend support to research (Caddell and Clare, 2010; Hyden and Orluv, 2009; Twigg, 2010) that clients show awareness and that identity is maintained at the later stages of dementia; by '*being with*' staff were able to have these interactions which helped to see the person.

However, there were contradictions within participants' accounts, saying at one point that people could not communicate but later talking about interactions with people based on non verbal methods. This suggests that too much emphasis is placed on verbal communication, and people who can only communicate non-verbally can initially be dismissed as being unable to communicate. In support of this, staff reported finding non-verbal communication difficult, as it was not like normal communication, suggesting a training need. This illustrates the danger referred to above, that clients with non-verbal communication can be isolated, and highlights the need to challenge assumptions that not having verbal communication does not mean a person cannot understand or communicate.

Spending time with the person with dementia could increase possibilities of understanding the person and learning more about them. However, without this time and perseverance, communication could pose a barrier to connecting with clients. Some staff did not persevere or needed encouragement and others seemed to feel hesitant and unsure in whether communication was understood on either side. Whilst the utility of communication was suggested as key to helping maintain a person's identity, verbal communication was not essential but, rather, the positive effects of emotional and empathic interaction was highlighted. Reaching for a hand was one example of such emotional connection.

Kitwood (1997) suggests that it is important that staff receive feedback on how they are doing and it may be that there is little opportunity for this or discussion if these spaces are not made available. This lack of feedback could therefore further serve to undermine confidence. Not addressing the issue of communication increases the possibility of malignant social psychology. Staff's uncertainty of whether they are being successful in communication perhaps goes some way in accounting for the lack of interaction that is often seen in care

homes (Alzheimers Society, 2007; Ice, 2002). Yet relationships are a priority for wellbeing (Zgola, 1999).

Past research has pointed out that not seeing the person as a person may have got in the way of communication. However, many of the staff interviewed stressed the importance of not giving up, using themselves to reflect that, were they in the person's position, they would want others to try to communicate. It seemed then that staff believed in clients' ability to respond but were not confident that they would get it 'right' on initiating contact.

Being available also allowed time for clients to state preferences and gave an opportunity for staff to support these, which perhaps could facilitate a positive connection. However, there were examples where clients' views were not upheld, which threatened the relationship. In some cases this was done with the intention of protecting a client's physical health; in other cases it was less clear, but it could be that clients' views were not seen as valid, perhaps due to their cognitive impairment, or because staff felt they were in the position of expertise. Situations where people's preferences are not respected serve to threaten identity and suggested that not all staff were so in tune to people's emotions. It may be that beliefs about dementia or what staff's role is gets in the way of this. This highlights the power of staff and organisations in promoting or diminishing personhood and facilitating or diminishing relationships.

There were indications that spending time with the person brought many positive emotions for clients and staff, and helped them to 'see' the person. The use of life history had similar effects and this is supported by the existent literature (Batson et al., 2002; Kitwood, 1997; McKeown et al., 2010 and Stokes, 2008).

The positive implications of knowing about someone's life history have been supported in much of the research to date. This study offers further support, that knowing even a small piece of information or having access to memorabilia helped staff to connect with people, and this was particularly helpful when initially meeting clients. It helped to support peoples interests and reflect on peoples

past achievements enhancing the opportunity to connect and maintain identity as found by (Baldwin, 2008; Batson et al., 2002; Bender et al., 1999 and McKeown et al., 2010).

Not only was there evidence that staff held this knowledge but that that they kept bringing it back whether to promote interests, or achievements; staff aimed to promote wellbeing by keeping in mind people's stories. An example of this was staff helping regulate people's feelings by reminding them of positive stories when people were feeling low, knowing these had the power to evoke positive feelings. The use of LSW has reported these benefits but proponents of this method have perhaps been less clear about how, and to what degree, knowing about someone's history can be used in daily life. In this research there was evidence that people's stories were utilised but less information as to what degree carers shared this knowledge with colleagues.

In Batson et al.'s research on LSW (2002) their interviews with carers and the people who had gathered the information about the person with dementia for the LSW on the whole did not feel that it improved relationships. However, this structured intervention was based with people in their own homes. It may be that knowing history in a care home setting would have more potential to influence the care of someone in an unfamiliar environment. In addition their work did not follow up over time and it is unclear as to how they continued to use the LSW. This current research suggests that history can be held and brought back to clients in a way that has positive effects. The influence that life history can have resonates with the outcomes of reminiscence work, however this tends to happen in more structured settings. How much using history happens informally has been less clear (Brooker, 2011, McKeown et al., 2010).

The current study supported McKeown et al.'s (2010) findings that knowing a person's life history brought pleasure to staff and the person with dementia. Both exploring life history and 'being' in the moment seemed to invite opportunities for promoting personhood and seeing the person. Supporting these findings Pietrukowicz and Johnson (1991) found that LSW was important in building and

maintain relationships which are not only crucial to clients' wellbeing but also staff's (Parsons, Simmons, Penn and Furlough, 2003). In addition in this current study, knowing history enabled staff to provide familiarity to clients and, therefore, a psychologically safer environment supporting the idea that knowing history contributes to person-centred care and can be used day-to-day.

Where a person could not convey much about their past, staff's reliance on family's knowledge about them increased. Family were often referred to when staff spoke about getting to know the person; families were a resource to providing history, and this was felt a useful starting point in building a relationship, as they also had access to memorabilia. Some staff recognised sharing their relatives' histories also seemed important for families. This is supported by research suggesting that families want to be actively involved and share their 'expert' knowledge, although it is often rare for staff to draw on family's expertise (Davies and Nolan, 2006). Being interested in the person with dementia was felt to be one way staff could begin to build relationships with family and often staff felt families were only too happy to share.

Although families were seen as a resource by all participants, staff varied in how active they were in seeking out relatives to ask more about a person. This is supported by Davies and Nolan's (2006) research in which relatives indicated they generally had to take initiative to continue to play an active role in care. In the current study, it was often the more senior staff who talked about approaching families to find out more and ask about their emotional needs. When they did approach families, discoveries were often made which helped explain behaviour or how to meet a need. It may have been that other staff did not see it as part of their role, for example, to seek out family outside of visiting hours, or that they did not feel empowered to do so, yet it has been argued that this is one of care home staff's key roles (Lundh, Sandberg, Nolan, 2000). Other possible explanations are that staff did not want to encroach on family, were worried about being judged, or just did not see finding out clients' history as a priority, perhaps not understanding the possible benefits of doing so.

The relationship of some staff with family seemed to have greater depth than just asking about their relative's past. As previous research suggests (e.g. Fossey, 2010), understanding the implications of the move for the person and family is key in developing relationships with them. Managing guilty feelings and worrying about the quality of care their relative will receive (given press reports about homes) are just some of the experiences that families need to be supported with. However, there is a question as to whether all staff were able to recognise the emotional needs of family and attend to them. This links to earlier discussion on attending to staff's emotional needs in order for them to be more emotionally available to help others).

It has been suggested that staff are often not aware of their role of supporting families in adjusting (Hetzberg and Ekman, 2000), yet often families are entering a new world where admission occurs quickly, often with no prior visit. Sandberg, Nolan and Lundh et al. (2000), proposed that staff have different levels of awareness with 'empathetic awareness' being most common, with many staff being conscious of how hard it must be for relatives to make the decision – indeed, a major life event. In their study staff created an opportunity for spouses to talk about their feelings. 'Empathetic awareness' suggests that staff valuing the knowledge of the cared for person was demonstrated by discussing this with the relatives. They found other staff were more 'guarded' or had 'limited' awareness, resulting in them being more reserved and viewing relatives as demanding and critical of care. This detachment could for example, be a result of a lack of confidence and it seems important to perhaps consider what informs the differences in approach.

Further, Lundh et al. (2000) suggested there was a need to better prepare spouses for separation and also to help them maintain their relationship with their partner and form new relationships with staff .

Those that could recognise families' emotional needs were often able to suggest to families possible strategies to connect and they believed these worked. These members of staff may have felt more contained and therefore were able to think

about and offer this, but also perhaps had a greater understanding of the rationale behind some of the more psychological interventions. They tended to be staff at a more senior level, perhaps also indicating higher levels of training and access to ideas, as well as greater confidence. One of these was a manager with a mental health background and two were senior staff from site three, suggesting a feeling-based ethos may help staff to be attuned to families' needs. Other staff may have ideas but did not have the confidence or power to take these forward.

If staff can support family to feel more able to be with residents this could foster relationships between staff and family, family and client, and staff and client, which was made explicit by one participant. However, to do this effectively staff are likely to need containment and a good understanding of the importance of being, history and family- not just 'doing' person-centred care but embodying person centred care.

Hertzberg and Ekman (2000) proposed several factors which could determine whether a 'we', or 'us and them' relationship was formed between staff and family: i) whether or not there were opportunities to influence care, ii) limited communication in both directions in terms of relatives not being able to obtain information and not being informed and iii) how lack of communication could result in a perceived lack of knowledge of the person's needs and history. It seems that for knowledge to come forth good relationships are a prerequisite. Kitwood (1997) proposed that breaking down barriers enabled staff and family to better 'share the care', which would mean family could feel more comfortable about their loved ones getting the care they would want them to have, without always being present.

As clients are now often more cognitively impaired on admission to care homes, due to the drive to keep people at home, families are increasingly important sources of information, in addition to complementing the care provided by spending time with the person with dementia. The ideas of LSW or memory boxes could be used by families with the person and others involved in care

being more involved in the transition to residential care and care planning. In Kent and Medway (Kent and Medway Partnership Trust: KMPT, 2011), psychologists have produced a leaflet on this work, which encourages anyone to attempt to record their life history if they are interested. Knowing life history helps care, therefore, it is very important that relationships with relatives are built. Indeed relatives can offer substantial resources not only to their relative but to other residents, as often they include others in conversation, yet Nolan and Davies (2006) suggests this is often not recognised. In addition less is known about families who do not visit care homes, and it may be helpful to research what may help to connect with them, bearing in mind the potential impact this could have on a client's wellbeing. It is important to think how staff can develop this empathic awareness and be encouraged to see a usefulness in supporting families and being proactive. The benefits cannot perhaps be realised until the problem is recognised.

This theme highlights the importance of psychological wellbeing and relationships, with some indication from participants that this is what clients also appreciate. This is in line with Clare et al.'s (2008a) findings and recommendations that folloed from interviewing people with dementia in care homes for example to provide more support to maintain role identities, engaging with residents life stories and past memories and facilitating opportunities to continue social roles.

## **4.2. Critical review**

### **4.2.1 Methodological considerations**

Participants consisted of care assistants and nurses, some of whom were at senior level, and therefore it is recognised this sample may be seen as limited in its lack of homogeneity. However, having a diversity of participants enabled a range of voices to be heard which added to the richness of the data. The larger sample from site two enabled a richer picture of potential organisational issues. This was less possible at site three and was not achievable at site one.

A potential complexity was that one of the care homes had received input from DCM and, therefore, staff were likely to be attuned to feeling-based care. On reflection, it was inevitable that interviews across homes would highlight differences and that organisational values would interact with staff's. However, site three is likely to have been significantly different to most homes in the UK due to its influence from DCM. It may have been that this home was agreeable to taking part due to its reputation and ongoing input and assessment by DCM, whereas other homes I tried to recruit from declined, as outlined in the methodology. Indeed the bad press around homes may have influenced other homes' willingness to participate, and I was aware that the Winterbourne View incident occurred around the time I was recruiting and that care homes may therefore be concerned about being exposed (Panorama, 2011). If I were to recruit again from care homes I would try and give more thought to what may help get homes on board, perhaps holding a focus group to generate further ideas here - otherwise only certain homes may come forward.

A further consideration is that it had not been the intention of this research to compare across homes. Consequently the conclusions that can be drawn between them are perhaps rather tentative as the methodology was not constructed in a way to enable a comparison.

#### 4.2.2 Recruitment

Before interviewing and approaching staff I had given some thought as to the influence of my position as a clinical psychologist in terms of how it might affect engagement and how staff might be in the interviews. I was mindful that some homes may feel threatened by someone outside of the organisation coming to do research, and tried to reassure managers and staff that it was aimed at hearing their experience rather than looking for right or wrong answers.

During one of the interviews I was struck by how one participant in a managerial role at points seemed to be promoting the home, commenting on what they were well respected for. This increased my awareness of the political and social context of participants and how we are always trying to project a role. It



encouraged me to think about how people in different positions may therefore represent their story in a certain way, as well as the limitations of interviews in assessing the reliability and validity of what happens in practice. Although it cannot be said for certain that participants' stories are representative of what is happening, it may be argued that they still offer a sense of people's outlooks, and perhaps their intended ways of practising. A way to triangulate the information gained in interviews would have been to observe staff in their interactions.

#### 4.2.3 English as a second language

For three people who took part English was not their first language. Of particular interest I felt was some of the language that was used was quite powerful, for example: 'we cannot even be human beings'. I considered that some statements may have come across as more direct or extreme as a result of English being a participant's second language. It could be argued that this participant is really 'saying it how it is' because they do not have access to language to temper this or communicate the message in a less stark way. Alternatively, this may be what they intended.

Going through this process has heightened my awareness of the importance of language when considering recruitment. Although perhaps not such a problem in TA I recognise the methodological difficulties that would arise if IPA, conversational or discourse analysis had been used and to bear this in mind in the future.

#### 4.2.4 Feedback to services

The findings to this study have not yet been fed back to staff. It would be interesting and beneficial to have shared my findings to see if these resonated with staff's experiences. Doing so may have helped to contextualise the data further and either confirmed the findings or offered different understandings. This would lend some weight to the reliability and validity of the findings.

Consideration as to how to feed back to the staff/homes will need careful thought in order to present the findings in a way that is constructive and validating of participants' experiences.

#### 4.2.5 Hearing the person with dementia

A limitation of the research to date is that it has not often included people with a diagnosis of dementia. Cohen (1991) argues that to improve ethical standards in clinical practice, we need to learn more about the person's subjective experience.

This has been highlighted as crucially important and needed in the literature and was a passion of mine when initially setting out my research proposal but due to some of the potential complications to be outlined it was not recommended due to restricted resources.

Bowers et al. (2009) and Milne (2010) highlight the limited research that has been done with individuals with dementia themselves. This is often reported to be a result of methodological challenges due, for example, to physical or cognitive difficulties.

The consequence has been, as in this research, that the people who get asked are those in the person's system. Although this has been helpful in building up a picture of individuals' experiences, along with measures of quality of life and observational tools such as Dementia Care Mapping, this approach is not sufficient and serves to prioritise other people's views over the person's, which is not only disempowering but also may not actually correspond to what is important to the person with dementia (Milne, 2011).

### **4.3 Reflective aspects of the research**

#### 4.3.1 The researcher's background

This piece of research was influenced by my prior experience of working in a care home as a care assistant, where work was often task-orientated and institutionalised, with far less time or thought given to people's psychological well being. Although I thoroughly enjoyed working with people with a diagnosis of

dementia and witnessed some positive interactions by some staff, I felt uncomfortable about a lot of the practices I saw, where people were treated as objects. While in this role, and subsequently, I have felt more could be achieved to improve an individual's wellbeing in the context of a care home environment, hence influencing my choice of area for research.

Later in my career, I had the opportunity to take part in some training based on Kitwood's (1997) ideas of person-centred care and worked within a service that was orientated towards these principles, which resonated with some of the ideas I had thought about as a care assistant. This experience increased my awareness of the stigma and negativity surrounding dementia, and the influence this context can have on individuals with dementia. These learning opportunities inspired me to think about what could be possible in care. For example, I considered one way to improve care was by drawing more on a person's personal history with the building of relationships between staff members and residents being crucial to facilitate this process. This corresponds with Kitwood's (1997) ideas and research into LSW and is where my research interest stemmed from.

I felt unable to do anything that would make a significant difference as a part-time care assistant and as a young student I did not feel I had the skills or confidence. Therefore having the opportunity as part of this doctorate has been significant to me, potentially giving me more power to influence care practice. However, I am conscious of the assumptions I have brought with me and the challenges that this research has brought, as well as great pleasure in hearing some staff's accounts and with the hope that I may be able to contribute to improving the lives of people with dementia in care homes.

#### 4.3.2 My assumptions and their impact

From my experience and the literature I have read on this subject area, I held assumptions that task-orientated care was still likely to dominate practice and that knowing the person was less likely to be valued and/or considered. I was also aware from the outset that I believed that knowing more about a person's

history would be beneficial for their care in building relationships and moving away from task-oriented care. However, I tried to reserve judgment and keep myself in check, reminding myself that this was something to possibly discover rather than to assume. Keeping a reflective journal and drawing on supervision supported me in this.

I became increasingly conscious of my assumptions whilst developing the interview schedule and I was concerned at points that these may get in the way of how the questions were constructed, or more importantly, influence my demeanour or responses in the interview. I identified early on this might be a problem and, therefore, drew on supervision to discuss interview questions and was careful to reflect on the language I used, particularly, in the pilot interview so this could be addressed. Reviewing this, there were a number of cases where I felt I had been leading, for example line 200-202 of the pilot interview:

Interviewer: *'Can you think of any other examples where it's been really helpful to know about someone's past history in terms of how it's affected how you work with them?'*

I spent time considering alternative ways I may have phrased questions and the process of supervision made me more self-aware to how I responded in the subsequent interviews.

In addition taking a critical realist position I recognise that my position may have influenced the coding of the data and therefore it is possible that someone else may analyse the data in a way that might produce a different perspective on the results.

#### 4.3.3 How this research has moved me

Although this research did highlight the benefits of utilising life history for clients as well as staff, it has opened my eyes to the potential complexities that may affect whether it is utilised in care homes.

When setting out on this research, my aim - and perhaps bias - was to be thinking about the clients and how difficult it can be for them, not considering staff may struggle with their own feelings. Reflecting on this I wondered myself whether I had not considered this because I had not worked in a context where space for a reflection had been a priority.

Listening to staff's experiences has been really valuable and has helped me to better appreciate their needs. I have been struck and surprised by how open staff have been about feeling scared and uncertain in managing behaviour and communication; there seemed to be a lack of confidence around for many staff and a need for containment. However, at the same time many showed strengths, resources, and commitment to working with people with dementia which I was impressed by.

I feel this research has been a good learning experience not only in terms of developing my research skills but clinically and I hope what I have learnt will help me consider staff's needs as well as clients in my future clinical role and, to be more aware of discourses and pressures at different levels for example, policy and management. I would hope to create spaces that feel safe for people to talk, which seems so crucial in providing and enhancing care.

#### 4.3.4 Balancing the role of the researcher and the clinician

During the interviews there were times when I became aware of almost taking on the role of a clinical psychologist rather than a researcher. There were occasions where I noticed that I felt I wanted to rescue or help a participant think further about a dilemma. I felt that this indicated a difficulty in balancing a clinical and research role – and made me more mindful of this for future interviews. Using supervision to sound the tension between these roles was helpful in normalising my experience and helping me to better manage and feel more comfortable in not rescuing participants.

## **4.4 Implications for clinical psychology**

### **4.4.1 Conclusion**

This research has highlighted some of the important factors which affect how care home staff get to know a person with dementia, their experience of this process and what can facilitate and get in the way of building relationships. The processes which occur before a person with dementia comes to live in a care home are important to consider in terms of what information is accessed, how it is communicated to staff and the effect perceptions of risk can have on building relationships and seeing the person, potentially posing a threat to the maintenance of a person's identity. Engaging with family seems crucial for all parties involved, enabling richer relationships, crucial to the person with dementia. Work is needed to make this happen.

Spending time with the person with dementia and discovering their life story can provide multiple opportunities for creating good, warm relationships and facilitating identity, which was often recognised as still being present in this study. Perhaps most importantly it can help clients to feel psychologically safer and help staff to know how to help and be with the person. Increased emphasis should be placed on doing more of this work, particularly by regulatory bodies.

The importance of safety and the need for containment is echoed through the system: from the client, the relative, the staff and the organisation. It is important to consider the social and political discourses which may be threatening this, with the emphasis on risk rather than trust, in health and social care systems. In agreement with Brown and Calnan (2012) this research suggests that focussing on risk gets in the way of focussing on, and building relationships with, the person.

If a safe and containing environment is to be created, there follows a question of staff's confidence to do so: confidence of carers to communicate with people with dementia and their families as well as to manage risk and uncertainty. This research and previous research suggests that addressing anxiety in the system, providing ways to help contain and attend to staff's feelings could help staff to

better attend to emotional and relational aspects of care, being more emotionally available and less task orientated. In other words, improving the wellbeing of staff will ultimately improve the wellbeing of those they work with.

Tensions between old and new cultures of care, and the breaking down of boundaries, need to be addressed and suggest the care system is still struggling to change, despite the aspirations of many staff to do so. This research supports existing literature (e.g. Sheard, 2004, 2008a) that suggests a feeling-based approach can help tackle many of the challenges staff face in building relationships with clients. What seems really crucial is tuning into staff's feelings to enable them to do the same for clients. The *nature* of training to help staff tune into their feelings is suggested to be more important than the *amount* in helping to produce change, but this needs to be continual and include staff at all levels (Kitwood, 1997; Lintern, Woods and Phair, 2000; Sheard, 2009).

All of these individual and organisational processes are likely to be influenced by the wider social, historical and political discourses as discussed.

#### 4.4.2 Further research

Although not its intended focus, this research yielded further information as to the difference a feelings-based training approach could make to staff's practice. However, this was based on a small sample. It could be helpful to conduct further research across homes with similar and different training backgrounds and it would be interesting to consider in more detail their perception and experience of risk. A combination of quantitative and qualitative methods may be useful in such research, to enable structured comparison, but also to yield further rich information.

Another area for further research is to hear more from the person with dementia and their experiences of living in a care home. Gradually there has been an increasing drive to include individuals with Dementia in research to express their views thereby influencing their care (DoH, 2009a); Murphy et al., 2010). Many

studies have highlighted the contribution individuals can make (Mozley et al. 1999; Train, Nurock, Manela, Kitchen and Livingston, 2004).

Research has predominantly relied on verbal communication and this has been a methodological challenge to capturing individuals' voices. However more creative research techniques are being developed and recommended for example using media and photography (Prosser, 2006; Craig, 2009) and using 'process consent' to meet ethical standards (Moniz-Cook, 2008, Wilkinson. 2002). However, this area still needs more attention.

In addition relatives' engagement with staff at care homes seemed crucial to relationships and it would be helpful to further investigate what makes particular relatives visit more or less often, and whether there are ways in which they could be further supported or facilitated to be more involved if they want this.

#### 4.4.3 Recommendations

In light of this study's findings a number of recommendations are proposed to help staff and clients build good relationships:

- For care home staff to reflect on the admission process to the home, with consideration given to what information is gathered, how this is shared, and what is prioritised.
- To encourage personal history and memorabilia to be gathered in a way that is accessible early on, not only to help staff see the person, but to enable the person with dementia to be as involved as possible in this process. Guidance could be produced for families as done by KMPT (2011).
- To consider what helps staff to regularly access and follow care plans and what would facilitate this further. A recent development which could assist here is a software communication package called 'Portrait' (Webster, 2011) with interactive multi-media presentations about a person's history,



to serve as a communication bridge between staff and clients, with a view to improving care, through staff learning about the person. However this should not be seen as a substitute for improving staff communication for example using photographs, talking mats and *being with* the person in presence or through touch. As this research has confirmed, the emotional connection with clients is crucial, with positive effects for staff, clients, relatives and the organisation.

- To be aware of the impact of perceptions of risk on the organisation, staff and client as well as being in touch with the social and political pressures and managing these in a way that does not create anxiety or hypersensitivity to risk throughout the system. This is important as this seems potentially toxic to developing good relationships and for the psychological wellbeing of those involved. The organisation's approach to risk should be reviewed and strategies to offer containment to staff, such as reflective spaces, should be implemented. Attending to staff's emotional wellbeing should have positive consequences for all those involved in the system.
- Society and politics also needs to be aware of problems that can occur due the emphasis on risk and consider the importance of attending to trust (Brown and Calnan, 2012) to truly attend to a person's needs. In addition, although policy has been emphasising clients' psychological needs (as outlined in the introduction to this thesis), this needs to be translated into practice, as emphasis on risk tends to override this.
- A number of training needs were highlighted from this study, stemming from a lack of staff confidence in some cases. Sheard (2009) has highlighted that training needs are often identified but awareness training does not result in a change of practice. Getting staff to experience what it is like to be the person with dementia, tapping into 'emotional intelligence'

is what is required to make a difference. Dupuis et al. (2012) suggest that how dementia and behaviour are understood is directly connected to teaching and learning processes provided to staff. Others have also supported this contention (e.g. Sheard 2009; Lintern et al., 2000). These methods are likely to increase staff confidence in being able to offer person-centred care, helping them to feel safer, and therefore better able to contain others.

- From reviewing the literature and the work of outside professionals who have been involved in facilitating reflective practice (including the utilisation of the Newcastle model with homes to better understand the person) it seems that better connections of care homes with health and social care services are likely to be beneficial. Support from these outside agencies could serve to both increase skills and resources in the home, and to help staff feel supported and contained. The process of formulation to understand the person could and should be done with all clients at admission and as part of the process of providing person-centred care.
- Individual supervision for every member of staff should be considered to provide containment and facilitate formulation. Peer supervision could be considered as an additive or alternative as when done well, this can have positive effects on staff learning and confidence.

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## 6. APPENDICIES

## Appendix A: Ethical approval form

### SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.  
uel.ac.uk/psychology



### Doctoral Degree in Clinical Psychology Direct Fax: 0208 223 4967

June 2011

Name of Student	Emily Blow
Title of Research Project	Staff perspectives on getting to know an individual with dementia.

To Whom It May Concern:

This is to confirm that the above named student is conducting research as part of the requirements for the Professional Doctorate in Clinical Psychology. The Ethics Committee of the School of Psychology, University of East London has approved their proposal and they are, therefore, covered by the University's indemnity insurance policy. This policy should normally cover for any untoward event provided that the experimental programme has been approved by the Ethics Committee prior to its commencement. The University does not offer "no fault" cover, so in the event of untoward event leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the above named is a student of UEL the University will act as the sponsor of their research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Kenneth Gannon PhD  
Research Director

Dr Martyn Baker 020 8223 4411 M.C.Baker@uel.ac.uk  
Dr Maria Castro 020 8223 4422 M.Castro@uel.ac.uk  
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## Appendix B: Information sheet

### Information sheet for staff

Dear staff member,

I am interested in hearing your perspectives on getting to know an individual with dementia.

Your employer supports the running of this project and has given permission for you to take part during working hours. Taking part is voluntary, and you can withdraw from the research at any time without having to give a reason.

The project would require you to meet with the researcher for 30 minutes to an hour at time that is convenient to you.

There are particular questions that everyone will be asked but also flexibility so that you can bring in your views and experiences.

Interviews will be audio recorded to enable more accurate analysis of data. This information will only be accessible to the researcher. All information that is collected during the research will be kept *confidential* and analysed *anonymously* by the researcher only (any identifiable details such as name will be removed). Information will not be shared with your employer unless there is concern about risk to yourself or others. Information about you and your study answers will not be disclosed in a way that identifies or links them to you at any point of the analysis, presentation, or publication of the findings.

Your time would be greatly valued and is important in promoting better quality of life for individuals with dementia.

If you are interested in taking part or have any questions please contact me on the telephone number or email address below.

Thank you for your time,

Emily Blow (Researcher)  
Trainee Clinical Psychologist  
07834 989 668  
u0933867@uel.ac.uk

Supervisor:  
Dr Maria Castro, Clinical Psychologist  
University of East London  
School of Psychology  
Stratford Campus  
Water Lane  
Stratford  
London  
E15 4LZ

## Appendix C: Consent form

To participate in this project please read and sign the form below

### Consent Form for Participants

- |  |                              |                             |
|--|------------------------------|-----------------------------|
| 1. <b>I have read/been read the enclosed information sheet</b> on the above project, and I have been given a copy to keep. <b>I have had the opportunity to ask questions</b> about the project and I understand why the project is being done.    | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 2. <b>I agree to participate in the project and for the interview to be recorded.</b> I am free to withdraw at any time without giving a reason.   | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 3. <b>I give permission for short extracts from my interview to be used</b> in the final report, and any subsequent journal publications and reports. These extracts will be anonymous, with all personally identifying information being removed. | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 4. <b>I know how to contact the person running the project if necessary.</b>   | <input type="checkbox"/> YES | <input type="checkbox"/> NO |

Name of Researcher	Signature
--------------------	-----------

Name of Participant	Signature
---------------------	-----------

Date
------

## Appendix D: Standardised letter/email

Emily Blow (Researcher)  
Trainee Clinical Psychologist  
University of East London  
School of Psychology  
Stratford Campus  
Water Lane  
Stratford  
London  
E15 4LZ

Email: [u0933867@uel.ac.uk](mailto:u0933867@uel.ac.uk)

Telephone: 07834 989 668

Manager name & address

Date:

Dear Home Manager,

I am currently training at the University of East London for a Doctorate in Clinical Psychology. Earlier this year I put in a proposal to the UEL Ethics Committee to carry out a piece of research to explore staff perspectives on getting to know individuals with dementia in a residential/nursing home care setting. It has now been approved for the study to go ahead.

I am looking for approximately 10 members of staff across several residential/nursing homes. The study would involve interviewing staff about their experiences and views of working with individuals who have a diagnosis of dementia. Interviews will take between 30 minutes to an hour and can be arranged at a time convenient to the staff member, for example, in or outside of work. All information will be kept confidential and will be anonymised. I will ask for permission to audio record the interview to enable more accurate transcription and analysis of the data. Staff are free to withdraw at any point during the study.

Staff are recognised as a valuable resource to care provision and their contribution will help increase our knowledge of what works well, how, and why, in supporting individuals with dementia. This will then enable us to build on good practice. In addition, it is recognised that the demanding and practical nature of care work can sometimes make it difficult for staff to find time to share their experiences with others and reflect on their practice. I therefore hope that this research will give staff some space for this and will be a useful process for them, potentially having an impact on their own practice.

As you may be aware it can be difficult to recruit people to take part in research and the area of dementia care is an important area to build on. If you have any questions and/or would like to know more please do contact me. I would be happy to meet with yourself and/or the staff team to discuss this study further.

Thank you for your time, I look forward to hearing from you.

Kind Regards

Emily Blow (Researcher)  
Trainee Clinical Psychologist  
07834 989 668  
[u0933867@uel.ac.uk](mailto:u0933867@uel.ac.uk)

Supervisor: Dr Maria Castro,  
Clinical Psychologist  
University of East London  
School of Psychology  
Stratford Campus  
Water Lane, Stratford  
London, E15 4LZ

## **Appendix E: Socio-demographic form**

**Site Number:** .....

**Participant Number:** .....

### Screening criteria (inclusion/exclusion)-

- Experience of working with people with dementia- 9 months
- Good level of English

### Background information on staff

1. Age
2. Gender
3. Ethnicity and country of origin
4. First language
5. Years of experience working in dementia care
6. Prior experience and roles held
7. Current job role/position



## Appendix F: Interview schedule

**1. Can you tell me what happens when you find out an individual is coming to the home? What happens when they arrive? How do you find this process? What is it like?**

**2. Are there opportunities to get to know an individual?**

Prompts: What is your experience of this? What helps? What are the challenges? Time? Communication? Is training given?

**3. What information do you tend to know about the individuals that you work with?**

**How do you get to know this information? What is your experience of finding this out?**

Prompts: what/how do you access/gain information about an individual?

**4. What information if any do you think you need to know/is important to know to work with someone well? *Prompt question(s):***

Is there any information that is helpful? What sorts of information about them, about their situation, their lives, their backgrounds, how they communicate, their daily routine? Does knowing information make a difference to your relationship/how you work with them?

*Ask for example:* Think of a particular client/resident. What helps you to work with them? What things did you ask about? What made you ask about these things? When did you find out this information? What would it be useful for you to know or understand about them?

*Ask for example:* Think of a particular client/resident. What else would you be interested to know about this person? *Prompt question: What makes you curious to know this? Do you think that knowing this would influence the way you work with them in any way*

## **Appendix G: Transcript convention**

The following were included: incomplete sentences, pauses (recorded but not timed), repetition of words and laughter - the intention here being to add some additional context to facilitate analysis of the transcript by raters.

Transcribing conventions used were adapted from Banister et al. (1994)

- (.) Pause
- (inaudible) Inaudible section of transcript
- Emphasis
- [laughter] Laughter during the interview
- Where an interruption by another speaker is brief it is placed in a <> Chevron
- Other interruptions and overlapping talk are marked with /

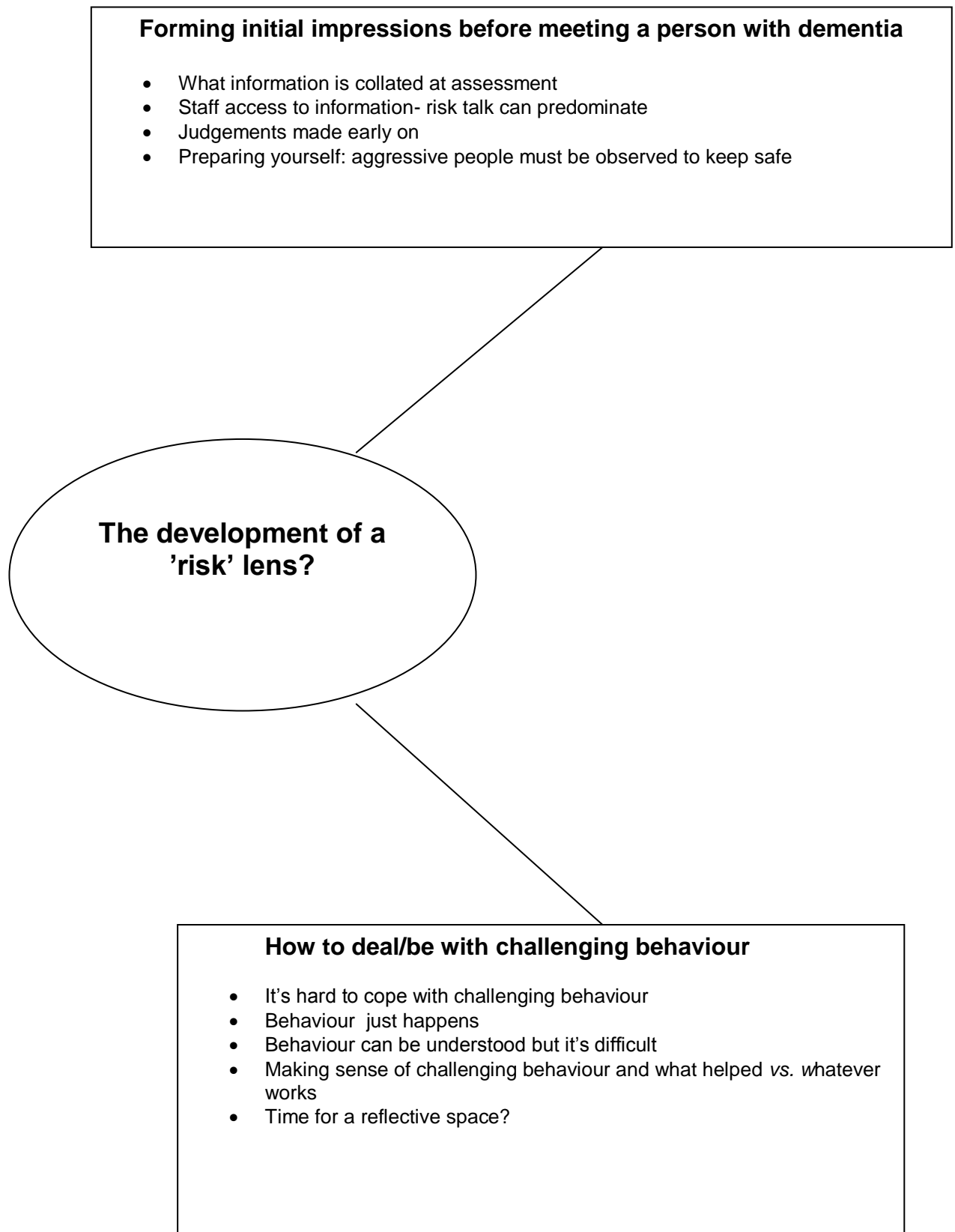
## Appendix H: The six phases of thematic analysis

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

## Appendix I: Coding example

203 and other residents sort of appear unaware of their change and their  
204 move and they sort of simply slip into within the family group straight  
205 away and then you have got others who are actually very very  
206 distressed at having to come in, erm and  
207 Int: how might they show that?  
208 P7: erm they can show it through all sorts of erm different ways, they  
209 can be quite physically aggressive, verbally aggressive, you know to  
210 themselves to other residents, to staff and again it's about (.), and the  
211 staff being that that focused and that spot on, to notice the little  
212 changes of somebody who is becoming a little bit agitated, to be able  
213 to step in and support them and calm them and divert them before  
214 they then push over and they are banging on the doors, because we  
215 also have a policy as well is if we have a resident who is becoming very  
216 very distressed on the residential side we will open that door for them  
217 we will remove that barrier that is causing them so much distress we  
218 will open the back door for them so that they can go outside, I mean  
219 we can't sadly allow them to go back because quite often they will ask  
220 for home, where's home, again it's a feeling it's not actually something  
221 that, they probably are trying to get home but in their mind home is  
222 where they feel safe, secure and warm and that's not what that  
223 moment of time is being for them, it's a very cold and scary place, like  
224 when you have a lady who wants to get home to her boys, you know  
225 can quite understand I have two children of my own, someone is  
226 preventing me (yeah sure), come hell or high water I am getting out of  
227 this place so  
228 Int: and when you say family groups, what did you mean by family  
229 groups  
230 P7: Just us the staff, the residents  
231 Int: okay  
232 P7: because sort of when you walk on to that unit it's a family, you are  
233 a family, erm because otherwise it doesn't work, then it's trying to  
234 take away that, again that culture that has always been, that is  
235 breaking down of work is work and home is home and it's about  
236 incorporating and encouraging staff and family to talk about their  
237 home life to talk about different things, because if they are expecting,  
238 if we are expecting residents to talk about their family then we should  
239 be as open about that to them  
240 Int: so do you mean [telephone ringing]  
241 P7: this is my family [shows me picture]

## Appendix J: Thematic diagrams



**A family ethos: 'breaking down of work is work  
and home is home'**

- Seeing people as family
- The value of feelings created
- Staff bringing in their life
- Being mindful of boundaries

**Challenges in what is  
valued by staff and  
organisations: a need  
for congruency?**

**Bringing person centred care to the fore**

- Spending time with the person is valued
- Tasks are valued
- It's a personal responsibility to make time
- Priorities
- Hopes/moves for the future- reducing task orientated care

**Building relationships takes time and a commitment to 'being with'**

- *Being with* – tuning in to feelings
- *Being with* – a way of understanding/learning
- *Being with* – an opportunity to support the person's voice
- *Being with* – to see the person

**Utilising personal history in establishing and maintaining trusting relationships**

- Connecting
- Providing safety
- Regulating emotions
- Enabling personhood

**Creating fertile ground for building trusting relationships**

**The importance of valuing and supporting family**

- History from the family is key
- Coping with a 'guilty' decision
- Supporting the family with 'dementia'
- Supporting the family to support and 'be with' the person